ADVOCACY IN HEALTH CARE

Teaching Patients, Caregivers, and Professionals

ADVOCACY IN HEALTH CARE

Teaching Patients, Caregivers, and Professionals

Publisher's Note

This monograph is published by the Oncology Nursing Society (ONS). ONS neither represents nor guarantees that the practices described herein will, if followed, ensure safe and effective client care. The recommendations contained in this monograph reflect ONS's judgment regarding the state of general knowledge and practice in the field as of the date of publication. The recommendations may not be appropriate for use in all circumstances. Those who use this monograph should make their own determinations regarding specific safe and appropriate client-care practices, taking into account the personnel, equipment, and practices available at the hospital or other facility at which they are located. The editors and publisher cannot be held responsible for any liability incurred as a consequence from the use or application of any of the contents of this monograph . Figures and tables are used as examples only. They are not meant to be all-inclusive, nor do they represent endorsement of any particular institution by ONS. Mention of specific products and opinions related to those products do not indicate or imply endorsement by ONS.

ONS publications are originally published in English. Permission has been granted by the ONS Board of Directors for foreign translation. (Individual tables and figures that are reprinted or adapted require additional permission from the original source.) However, because translations from English may not always be accurate and precise, ONS disclaims any responsibility for inaccurate translations. Readers relying on precise information should check the original English version.

Printed in the United States of America
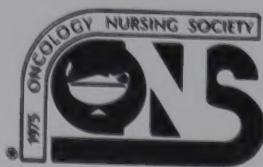
Oncology Nursing Society
Integrity • Innovation • Stewardship • Advocacy • Excellence • Inclusiveness
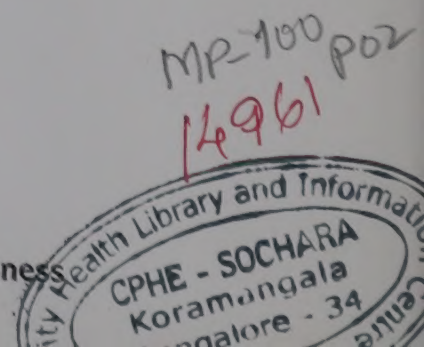
Contributors

Editors

Elizabeth G. Gomez, RN, MSN
Editor, ONS Online
Partner, Newtonnet Productions, LLC
Ridgefield, CT

Mary Gullatte, RN, MN, ANP, AOCN®, FAAMA
Director of Nursing
Winship Cancer Institute and Emory Hospitals
Atlanta, GA

Authors

Judy Lyter, RN, MS, NCC, LPC
Counselor in private practice
Chronically Ill Counseling, Inc.
Harrisburg, PA

Marnie McHale, RN, MS, AOCN®
Manager of Community Relations
Robert H. Lurie Comprehensive Cancer Center
Northwestern University
Chicago, IL

Eva D. Smith, RN, PhD, FAAN
Associate Professor
University of Illinois at Chicago
Chicago, IL

Planning Committee Biographical Information

Elizabeth G. Gomez, RN, MSN

Elizabeth Gomez is the editor of ONS Online, the official Web site of the Oncology Nursing Society (ONS). She is responsible for selecting, directing, and overseeing content on ONS Online. She also is the chair of the ONS Online Editorial Board. Ms. Gomez obtained her BSN at Villanova University in Villanova, PA, and her MSN at Columbia University in New York. She served as a clinical nurse specialist at Memorial Sloan-Kettering in New York and is the founder of Newtonnet Productions, LLC, a health information company. She is a frequent speaker on healthcare information on the Internet. Ms. Gomez has no vested interests with a commercial concern directly or indirectly related to this continuing education activity.

Mary Gullatte, RN, MN, ANP, AOCN®, FAAMA

Mary Gullatte is the director of Nursing Oncology Services at Emory University Hospitals and Winship Cancer Institute in Atlanta, GA. She has administrative responsibility for inpatient services for two hospitals and serves as the liaison for oncology nursing standards across Emory Hospitals and Clinics as well as two partnering hospitals. Ms. Gullatte began her nursing career with an associate's degree in nursing from Okaloosa-Walton Community College in Niceville, FL. She obtained her BSN from the University of Southern Mississippi in Hattiesburg and her master's degree in nursing from Emory University. She also completed a post-master's Acute Care Nurse Practitioner program at Emory University. Ms. Gullatte is an adjunct clinical faculty member at Emory University and was responsible for the development of the Oncology Nursing Residency Program for Emory University Hospitals. She has presented on multiple occasions for ONS educational programs, including the ONS Annual Congress and the Leadership Development Institute. She is the editor of *Clinical Guide to Antineoplastic Therapy: A Chemotherapy Handbook*, which was recently published by ONS. Ms. Gullatte has no vested interests with a commercial concern directly or indirectly related to this continuing education activity.

Judy Lyter, RN, MS, NCC, LPC

Judy Lyter is a counselor in private practice with Chronically Ill Counseling, Inc. She counsels patients, caregivers, and families and serves a nurse educator. She obtained her diploma in nursing from Hartford Hospital School of Nursing in Hartford, CT, and continued her education by earning her BSN from Penn State University in State College, PA, and her master's degree in community counseling from Shippensburg University in Shippensburg, PA. She served as an oncology nurse at the Penn State/Hershey Medical Center for 17 years. She has been a facilitator of cancer support groups and has served as an Oncology Nurse Educator through Oncology Education Services, Inc. She is a board member of her local American Cancer Society chapter and an active participant on the patient education committee. Ms. Lyter is a member of the speaker's bureau for Ortho Biotech Products.

Marnie McHale, RN, MS, AOCN®

Marnie McHale is the manager of Community Relations at the Robert H. Lurie Comprehensive Cancer Center at Northwestern University in Chicago, IL. She is responsible for community education and outreach. She chairs the Patient and Family Advocacy Advisory Board, works with patient advocacy organizations, and plans educational programs for patients and the community. She also serves a member of the National Cancer Institute Cancer Patient Education Network (CPEN). Ms. McHale obtained her BSN from Northern Illinois University in DeKalb, IL, and her MSN, specializing in oncology nursing, from Rush University in Chicago, IL. She has presented on a variety of cancer-related topics at the regional and national level. Ms. McHale has no vested interests with a commercial concern directly or indirectly related to this continuing education activity.

Eva D. Smith, RN, PhD, FAAN

Dr. Eva Smith is an associate professor at the University of Illinois in Chicago. As a faculty member, she spends 75% of her time in a faculty role and 25% of her time as director of a program for underserved nursing students. Her faculty role includes teaching undergraduate and graduate students, conducting research, and providing service to the university, community, and the nursing profession. Her primary teaching areas involve the interaction between health, policy, and the environment, and her primary research interest is in breast cancer. She obtained her bachelor's degree in nursing from Winston-Salem State University, her master's in nursing education from DePaul University, both in North Carolina, and her PhD in adult and continuing education from Kansas State University in Manhattan, KS. She was the lead person in designing and implementing the BSN curriculum at Alcorn State University. She plans seminars and workshops with the Illinois Nurses Association and the Urban Health Program. Dr. Smith serves as the program and committee chair for the Chancellor's Committee on Status of Blacks and plans health programs with the caring ministry of her local church and the Health Ministry for the national church. She has published articles related to breast cancer survivorship among African American women and screening and early detection among racial and ethnic minority women. Dr. Smith has no vested interests with a commercial concern directly or indirectly related to this continuing education activity.

Table of Contents

To get a free copy of *Cancer Survival Toolbox: Building Skills That Work for You,* call the toll-free number 877-TOOLS-4U (866-5748) or visit the Web site of the National Coalition for Cancer Survivorship at www.canceradvocacy.org. From the Web site, you can listen to an audio version of the toolbox. This Web site requires Real Audio or Internet Explorer version 4.0 or greater to listen.

Cancer Survival Toolbox was developed by the National Coalition for Cancer Survivorship, the Oncology Nursing Society, and the Association of Oncology Social Work through an unrestricted grant from Genentech BioOncology. A facilitator's manual is also available.

Overall Learning Goal

The goal of this resource is to provide healthcare professionals with an overview of the skills that increase their effectiveness as they empower patients and caregivers to become self-advocates.

Learning Objectives

After reading this resource, the reader will be able to
• Define advocacy and self-advocacy.
• Define commonly used Internet terms.
• Explain criteria used for evaluating the credibility of Web-based information.
• Explain five basic communication skills.
• Present strategies that will help patients and caregivers to communicate effectively with healthcare professionals and providers.
• Compare two decision-making approaches and how they can resolve issues that patients with cancer experience.
• Discuss how patients can prepare to negotiate their care with healthcare professionals and providers.
• List credible sources that report on healthcare policy and discuss how a nurse can influence healthcare policy.

Introduction

The road to health care has become increasingly complex and difficult for patients and caregivers to navigate. People faced with the diagnosis of cancer often discover a path that seems more like an obstacle course than an expressway. Conflicting or confusing instructions from multiple healthcare providers, frustrating insurance systems, concerns about employment, and information overload create a daunting environment that few would choose to explore.

Nevertheless, each year more than one million Americans with cancer are forced to travel this difficult road. Oncology nurses and other healthcare professionals can be advocates for patients, easing their way through the healthcare experience.

Some, such as Senator Dianne Feinstein (D-CA), believe that a single provider should coordinate each patient's care. According to Feinstein's plan, which she proposed in Senate bill 1976 (the National Cancer Act of 2002), the coordinator would act as a "cancer quarterback," eliminating conflicting instructions, clarifying issues for the patient and caregiver while addressing his or her concerns, and serving as an advocate for the patient.

The cancer quarterback approach may well benefit patients and caregivers because it assigns the advocate's role to one person, someone in the healthcare system who has the power to implement the patient's directives. In a sense, however, the quarterback approach does not represent a break from traditional thinking in that the patient is dependent on a healthcare professional, the cancer quarterback, to advocate for him or her.

The premise of this resource is that patients and their caregivers can learn the skills they need to advocate for themselves. This premise is a modern application of the thinking expressed by Chinese philosopher Lao Tzu, who wrote, "Give a man a fish and you feed him for a day; teach him how to fish and you feed him for a lifetime."

Since 1999, a popular tool to promote advocacy skills in the healthcare setting has been *Cancer Survival Toolbox™: Building Skills That Work for You*, a resource published by the National Coalition for Cancer Survivorship, Silver Spring, MD. *Cancer Survival Toolbox* was developed to help anyone who is facing hard decisions and changes as a result of a cancer diagnosis. Originally designed as a series of six audiotapes, the program has been expanded and reformatted. Now it is available as a series of nine audiotapes or on a CD-ROM. The topics the resource addresses are communicating in the healthcare context, finding information, making decisions, solving problems, negotiating, standing up for rights, and finding ways to pay for cancer treatment. The resource also includes sections that discuss issues of special interest to older people with cancer and a section about caring for the caregiver. The tool is also available in Spanish.

The Oncology Nursing Society (ONS) developed *Advocacy in Health Care: Teaching Patients, Caregivers, and Professionals* as a resource tool for healthcare professionals to teach four key self-advocacy skills:
• Communication
• Information management (in particular, management of information from the Internet)
• Decision making
• Negotiation.

This resource provides an overview of each skill and presents relevant case studies, resources, and references. It may be used as a self-study module or as the basis of a program that oncology nurses present to patients, caregivers, or other healthcare professionals.

By teaching patients and caregivers to speak up for themselves, healthcare professionals can remove many of the bumps, twists, and navigation challenges of the cancer experience.

Chapter 1: The Advocacy Needs of Patients With Cancer and Cancer Survivors

Elizabeth G. Gomez, RN, MSN
Marnie McHale, RN, MS, AOCN®

Chapter Goal

The goal of this chapter is to describe the primary advocacy needs of patients with cancer and show how healthcare professionals can help patients to protect their rights and meet their advocacy needs.

What Is Advocacy?

The two senses of the word *advocacy* are evident in the definition of its root word, the verb *advocate*. To advocate means to plead for the cause of another or to defend one's own cause. *Advocate* comes from the Latin words meaning to summon a voice.

In the context of health care, *advocacy* can refer to the actions of a healthcare professional who defends, or gives voice to, a patient's interests. By teaching the patient advocacy skills, the professional empowers the patient to advocate for him- or herself, or to self-advocate. Empowerment is increasing someone's capacity to influence other people and the organizations that affect his or her life (Gray, Doan, & Church, 1991).

To self-advocate, the patient must understand his or her own needs and have the ability to communicate those needs to family, friends, and caregivers (Morra, 2000). Effective communication requires the ability to find information, make decisions, and negotiate.

This resource will teach oncology professionals how to empower patients through self-advocacy by teaching four skills as they relate to the cancer context: effective communication, how to find and manage information, decision making, and negotiation. Clark and Stovall (1996) suggested that learning and using basic self-advocacy skills can lead to successful adaptation to cancer as well as enhancement of one's sense of empowerment over the situation.

What Are a Patient's Advocacy Needs?

The Need to Advocate for Quality Cancer Care

To best assist patients in advocating effectively for quality cancer care, the oncology healthcare professional must have a clear definition of
- What constitutes quality cancer care
- What rights patients have in receiving that care.

What Is Quality Cancer Care?

According to the Oncology Nursing Society (ONS), quality cancer care is
- Accessible to all
- Timely
- Available through systems that provide reimbursement for costs
- Comprehensive and multidisciplinary
- Culturally competent, ethical, and cost-effective
- Delivered by accountable professionals with credentials appropriate to the specialty.
(To see the ONS position on quality cancer care in its entirety, see Appendix C.)

What Are Patients' Rights in Receiving Care?

Patients' rights are defined in patients' bills of rights. In negotiating the healthcare system, patients encounter patients' bills of rights at many levels. They can be specific to an institution, an insurance company, a state, or a professional organization.

Institution-based bills of rights. Many patients first encounter a patient's bill of rights when they visit a local hospital or clinic. Institution-based bills of rights often are included in patient handbooks or admission packets and are posted in hospital waiting rooms and lobbies. What rights does your institution's patient's bill of rights guarantee?

The U.S. healthcare system comprises many different options in regard to health insurance. Insurance can be publicly or privately funded or funded by an employer. Plans vary in terms of the "privileges," coverage, and rights afforded to the patient. All insurance companies offer a patient's bill of rights. Many health maintenance organi-

zations (HMOs) and preferred provider organizations (PPOs) also offer bills of rights. In general, a patient's bill of rights addresses six topics.
- Access to health care
- Healthcare claim review
- Information disclosure
- Grievance procedures
- Independent review of consumer appeals
- Health plan liability.

Unfortunately, most people with health insurance do not worry about their rights as patients until they get sick. When they are sick, they may let opportunities to exercise rightful options pass by because they are unaware of them. They may not notice rights violations immediately; take steps to preclude violations; or self-advocate in early stages, when problems are most easily fixed. As a healthcare professional, encourage each patient to review—*before* a health crisis—the patients bill of rights that his or her insurance provider, HMO, or PPO provides and publications that explain the details of coverage. These documents often contain terms and abbreviations that are specific to the insurance industry and medicine. As a result, understanding the documents may take some effort. (Appendix A may be helpful in translating terms and abbreviations used in the insurance industry.) Working through this information for the first time is not a job a patient should undertake when distracted by illness. If the patient faces such a situation, encourage help from friends or family members.

Cancer survivors face unique challenges in purchasing insurance and negotiating with insurance companies to ensure ongoing quality cancer care. *What Cancer Survivors Need to Know About Health Insurance*, a booklet published by the National Coalition for Cancer Survivorship, explains the types of insurance, provides tips about how cancer survivors can get the most out of their coverage, and discusses laws that provide insurance protection for cancer survivors who change jobs. (Visit www.cansearch.org or call the toll-free number 877-TOOLS-4U (866-5748) for information about getting a copy of the booklet.)

State legislation about patients' rights. Currently, no national law defines patients' rights in the United States, so patients' bills of rights vary from state to state. Many contain similar components, but differences do exist from state to state. To review the patients' bill of rights for your state, search the Internet by using *patients rights* and the name of your state as index words (see Chapter 2 for details). The office of your state senator or legislator also should be able to provide information, and the state medical society is another source of patients' rights information relevant to your state.

Rights as Defined by Various Professional Organizations

Organizations dedicated to meeting the needs of oncology healthcare professionals also are helping to define

quality cancer care through patients' bills of rights and position statements. Figure 1-1 shows the ONS Patients' Bill of Rights for Quality Cancer Care. Appendix C presents the ONS Position Statement on Quality Cancer Care. Appendix D is the American Society of Clinical Oncology Statement on Access to Quality Cancer Care. Review all these documents to ensure that you grasp the issues relating to quality cancer care and how prominent professional organizations recommend they be handled.

The Need to Advocate for Rights as an Employee With Cancer

Hoffman (1997) estimated that, in the United States, approximately 25% of individuals living with a medical history of cancer experience some form of employment discrimination. Specific problems reported by cancer survivors include
- Dismissal
- Failure to be hired
- Demotion or denial of a promotion
- Denial of benefits
- Undesirable transfer
- Mandatory medical examinations.

In addition, many cancer survivors experience misunderstanding, alienation, and hostility from their coworkers. In general, efforts to identify the unique employment concerns and issues facing cancer survivors are complicated by individual factors that can affect the employment situation. These factors include the worker's age, gender, and personality; the type of cancer and its stage at diagnosis; the worker's income level and his or her type of occupation; and the nature of any prediagnosis work problems.

Unfortunately, some employment-related problems that cancer survivors face stem from lingering myths about cancer. One myth is that being diagnosed with cancer always is a death sentence. Another is that cancer is contagious. An especially cruel myth maintains that cancer survivors are an unproductive drain on the economy.

Oncology healthcare professionals can play an important role by helping cancer survivors use self-advocacy skills to manage their work problems and counter myths with facts. In particular, cancer survivors need skills to navigate their relationships with employers and coworkers. These relationships may involve identifying and implementing necessary job accommodations, negotiating changes in employment or work responsibilities, or advocating for legal interventions when discrimination is suspected. The self-advocacy skills outlined in the *Cancer Survival Toolbox™: Building Skills That Work for You* (which the introduction of this resource describes) can be especially useful in dealing with specific work-related situations. With effective communication skills, the cancer survivor can maintain open dialog with an employer and coworkers during and following cancer treatment.

In cases in which an on-the-job accommodation can help the cancer survivor to perform work-related duties,

Figure 1-1. Oncology Nursing Society Patients' Bill of Rights for Quality Cancer Care

The board of directors of the Oncology Nursing Society approved this bill of rights in July 1998 and revised it in October 2000 and December 2000.

The Oncology Nursing Society (ONS), a professional association representing more than 30,000 registered nurses and other healthcare professionals specializing in cancer care, believes that quality cancer care is every individual's right. These rights include

- Availability of and access to education about cancer risks and lifestyle changes that influence the incidence of cancer, including educational activities that are effective and appropriate for diverse populations.

- Receipt of information in a timely manner in terms that can be understood, including unbiased analysis and interpretation of data, assistance in interpreting information relevant to medical status and treatment, and ample opportunity to ask questions.

- Reimbursement for screening activities that facilitates the early detection of cancer, when a greater potential for cure exists, including the use of genetic testing and counseling if the patient so chooses. These screening activities should be tailored to individual risk factors, including family history, age, race, gender, and socioeconomic status.

- Timely access to and healthcare coverage for the appropriate spectrum of treatment options provided in the most appropriate setting for the management of the specific cancer and symptoms, with active participation in treatment decision making in an informed manner. These treatment options include but are not limited to surgery, radiotherapy, chemotherapy, hormonal therapies, marrow and peripheral blood stem cell transplant, complementary therapies, rehabilitative therapies, and appropriate psychosocial services.

- Administration of cancer care by qualified healthcare providers, with specialized knowledge, who successfully complete ongoing programs that demonstrate their competency.

- Access to adequate healthcare coverage for supportive therapies that help to decrease the side effects of cancer treatments.

- Access to and healthcare coverage for the routine care costs of scientifically sound and culturally relevant clinical trials that follow research guidelines; provide informed-consent agreements; and yield information to advance the implementation of effective screening, diagnostic, and treatment modalities.

- Access to long-term follow-up, by oncology specialists, that focuses on health promotion, prompt detection and treatment of cancer recurrence, and the evaluation and identification of physical and psychosocial effects of cancer and its treatment.

- Availability of palliative care modalities that improve quality at the end of life, with a focus on symptom management, excellent pain control, psychosocial support for patients and families, hospice care, and bereavement counseling. This care must be provided in a manner that respects the individual's cultural, spiritual, and ethical needs.

- Respect for confidentiality consistent with legal and ethical guidelines.

- Access to care that is culturally competent. Each patient should be seen, heard, and respected as an individual, with individual differences related to needs and preferences as well as cancer characteristics.

---

problem-solving skills can guide him or her in requesting the accommodations. Knowledge about the laws that protect against employment discrimination and the ability to use that information can help the cancer survivor stand up for his or her rights in the workplace. Negotiation skills are vital to gaining job advancements, obtaining adequate health insurance, and protecting against unwarranted job dismissal.

Oncology healthcare professionals can guide cancer survivors to the important information they will need as employees. Figure 1-2 presents a list of general employment

resources. Figure 1-3 lists contacts in regard to filing employment complaints. Oncology healthcare professionals should have a general understanding of federal legislation that may pertain to their patients' employment interests. The remainder of this section will describe such legislation.

The Federal Rehabilitation Act of 1973

This act prohibits discrimination by employers that receive federal funding or federal contracts of more than $2,500; furthermore, it requires such employers to "take

Figure 1-2. General Employment Resources for Cancer Survivors

Job Accommodation Network (JAN)
JAN is a free service that provides information about job accommodations, the Americans With Disabilities Act, and the employ-ability of people with disabilities. JAN is funded by the U.S. Department of Labor Office of Disability Employment Policy.
Web site: www.jan.wvu.edu
Toll-free telephone: 800-526-7234
E-mail address: jan@jan.icdi.wvu.edu
U.S.-mail address: P.O. Box 6080, Morgantown, WV 26506-6080

National Coalition for Cancer Survivorship (NCCS)
The only patient-led organization that serves survivors of all types of cancer and their families. NCCS seeks to influence policy in ways beneficial to the 8.9 million survivors in the United States, and it produces programs and products to help people with cancer navigate their experience. These include online resources (e.g., CanSearch Navigator, a step-by-step guide for the newly diagnosed patient), printed material (e.g., *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor*, *Working It Out: Your Employment Rights as a Cancer Survivor*, and *What Cancer Survivors Need to Know About Health Insurance*), and audio programs. Many of the resources are available in languages other than English.
Web site: www.cansearch.org
Telephone: 301-650-9127
E-mail address: info@cansearch.org
U.S.-mail address: 1010 Wayne Ave., Suite 770, Silver Spring, MD 20910

Oncology Nursing Society (ONS)
ONS is an international membership organization of more than 30,000 registered nurses and other healthcare professionals dedicated to excellence in patient care, teaching, research, administration, and education in the field of oncology. ONS produces educational programs for healthcare professionals; lobbies for legislative and policy changes that support quality cancer care; funds nursing research; and produces a variety of educational materials, including books, for oncology professionals.
Web site: www.ons.org
Telephone: 412-859-6100
E-mail address: customer.service@ons.org
U.S.-mail address: 125 Enterprise Drive, Pittsburgh, PA 15275

Social Security Administration
The Social Security Administration is the U.S. government agency that administers Medicare and Medicaid, old-age and survi-vors benefits, and unemployment compensation.
Web site: www.ssa.gov
Toll-free telephone: 800-772-1213
E-mail address: Use the electronic form that is part of the Social Security Administration Web site.
U.S.-mail address: Office of Public Inquiries; 6401 Security Blvd., Room 4-C-5 Annex; Baltimore, MD 21235-6401. (Local offices are sited throughout the United States.)

State Vocational Rehabilitation Agency
Contact your state department of labor, human resources, public welfare, human services, or education to learn the services your state offers and to find local contact information.

---

affirmative action to employ and advance in employment qualified handicapped individuals." The act defines "handicapped individual" as any person who has a physi-cal or mental impairment that substantially limits one or more of his or her major life activities, has a record of such impairment, or is regarded as having such an im-pairment. In addition, the act requires employers to pro-vide reasonable accommodations to employees and ap-plicants to enable them to fulfill their job requirements. The primary limitation of the law is that it only applies to employers receiving federal assistance or contracts.

The Americans With Disabilities Act (ADA)

Originally signed into law on July 26, 1990, the ADA took effect in 1992, prohibiting private employers from discriminating against a qualified employee because he or she is disabled, has a history of disability, or is re-garded as being disabled. This act currently applies to private employers with 15 or more employees. The ADA requires that employers reasonably accommodate an employee's disability, and it includes provisions relating to health insurance and job interviews. The act mandates

Figure 1-3. Resources for Filing Employment Complaints

Complaints Under the Americans With Disabilities Act
Contact the Equal Employment Opportunities Commission (EEOC) at the toll-free number 800-669-EEOC (3362) to obtain the location of the regional EEOC office in your area.

Complaints Under the Federal Rehabilitation Act
Contact the Coordination and Review Section, Civil Rights Division, Department of Justice, P.O. Box 66118, Washington, DC, 20530; telephone 202-514-4609.

Complaints Under the Family and Medical Leave Act
Contact the Employment Standards Administration, Wage and Hour Division of the U.S. Department of Labor to file a complaint. Find the regional office in your area by looking under "U.S. Government" in the local telephone book.

Complaints Under State Law
Contact the division of civil rights or the human rights commission in your state; you will find contact information under "State Government" in the local telephone book. Or call the Equal Employment Opportunity Commission at the toll-free number 800-669-4000 to learn which state agency can best serve you.

that, if the employer provides health insurance to employees, the employer must provide it fairly to all employees. The ADA specifies that, when interviewing potential employees, an employer cannot conduct a pre-employment medical exam until after offering the job to the applicant. During an interview, an employer can inquire about the applicant's health history only when a physical disability that might affect the applicant's ability to perform the job is visible. Employees with dependents who are cancer survivors cannot be discriminated against because of the employer's fear that the employee will miss work or file expensive insurance claims.

The Health Insurance Portability and Accountability Act

This act allows an individual to change jobs without the risk of losing insurance coverage. If a person had insurance through his or her old job for at least one year, the new employer cannot deny insurance coverage to him or her. This law also keeps insurance companies from making new employees wait a long time before they are covered.

The Family and Medical Leave Act (FMLA)

FMLA requires employers with 50 or more employees to provide up to 12 weeks of *unpaid*, job-protected leave for family members who need time off to address their own serious illness or care for a seriously ill child, parent, spouse, or a healthy newborn or newly adopted child. An employee must have worked at least 25 hours per week for one year to be covered by this law.

The Employment Retirement Income Security Act (ERISA)

If an employer funds its own health insurance plan, ERISA prevents the employer from firing the employee to cut off his or her health insurance.

The Consolidated Omnibus Reconciliation Act of 1985 (COBRA)

This law requires an employer who has at least 20 workers and who offers group health insurance to continue selling insurance coverage to an employee for 18 months after he or she leaves the employer's organization. In some cases, exceptions apply to extending COBRA coverage beyond the 18-month period.

References

Clark, E.J., & Stovall, E.L. (1996). Advocacy: The cornerstone of cancer survivorship. *Cancer Practice, 4,* 239–244.

Gray, R.E., Doan, B., & Church, K. (1991). Empowerment issues in cancer. *Health Values, 9,* 571–579.

Hoffman, B. (1997). *Working it out: Your employment rights as a cancer survivor.* Silver Spring, MD: National Coalition for Cancer Survivorship.

Morra, M.E. (2000). New opportunities for nurses as patient advocates. *Seminars in Oncology Nursing, 16,* 54–57.

Chapter 2: How to Find and Evaluate Internet Information

Elizabeth G. Gomez, RN, MSN

Chapter Goal

The goal of this chapter is to ensure that the reader is Internet literate and has basic Internet research skills so that the reader can help a patient to find Internet information and evaluate its credibility.

Introduction

A patient, family member, or caregiver who wants information about cancer and its treatment will find it in many forms: in books and articles at public or specialty libraries, in government publications, in patient education materials prepared by a medical publisher or healthcare organization, or from friends and family. Most patients have skills that help them to find and evaluate the credibility of such information. Many patients, however, do not have the skills they need to navigate the fastest growing source of medical information: the Internet. The technology itself is new and overwhelming to many older people—exactly the population most likely to need medical information. Furthermore, the Internet is a medium that a patient is likely to use alone, without the help of a librarian or some other expert who can guide the experience. Even those skillful in using the Internet may not be skillful in evaluating the credibility of Internet information. The fact that Internet information comes in a high-tech format sometimes lends it an aura of reliability that it does not deserve.

For these reasons, this chapter will focus on finding and evaluating information on the Internet. Whatever the source of a patient's information, however, always encourage the patient to discuss his or her research, and any questions research results pose, with a healthcare professional.

In an article in the *Journal of the American Medical Association*, Berland et al. (2001, p. 2612) chronicled the impact of the Internet on American health care.

The Internet is an increasingly important source of health-related information for consumers. One . . . survey estimated that more than 60 million U.S. residents went online in search of health information [in 2000] (Fox & Rainie, 2000). The online population is becoming more representative of the larger

U.S. population in terms of race, age, income, and educational attainment (Rainie & Packel, 2001). Among those who use the Internet, more than 70% report the health information they find influences a decision about treatment (Goldsmith, 2000).

Cyberchondriacs

110 million adults will go online to look for healthcare information this year. A figure up from 54 million in 1998. A March 2002 Harris Interactive Poll found that 80% of adults already online (54% of the total U.S. population) used the Internet to find healthcare information. Of those surveyed, 18% said that they did this frequently, and the average person surveyed visited the Internet three times per month seeking some type of healthcare information.

A larger report based on the 2001 U.S. Census data confirmed these results and added some additional insights. In *A Nation Online: How Americans Are Expanding Their Use of the Internet*, the U.S. Department of Commerce (2002) reported that 35% of all adults are seeking healthcare information online. Gender, race, and age did not make one more or less likely to use the Web for healthcare information. Searching for healthcare information was the most frequent online behavior for those 55 years or older: 42.7% used the Internet this way.

Internet Access in Patient Education Centers

People who have Internet access at home or work can tap the many sources of online cancer information. In September, 2001, 143 million Americans or 54% of the population was using the Internet either at home or at work. Two million new users join their ranks each month (U.S.

Department of Commerce, 2002). For those who are not, the availability of an Internet-enabled computer in a patient education center can enhance the convenience of accessing the Internet. A patient education center provides educational resources, in a variety of formats, to patients and their families, friends, and caregivers. A patient education center dedicated to cancer education usually includes an extensive library of up-to-date information about cancer, cancer prevention, early detection and treatment, and coping with cancer. This information reinforces and supplements information patients receive from the healthcare team.

Location, the availability of Internet "coaches," the availability of technical support if any, and funding are key ingredients in the successful integration of the Internet into a patient education center.

Ideally, the location of the computer terminal that is connected to the Internet will be convenient and private. Privacy is essential. Patient education center visitors will not use the Internet if their health concerns are visible to any passerby or other Internet users. If several terminals are in one room, consider adding partitions between them to increase privacy. Many of those using public terminals may not have experience using the Internet to search for medical information. The availability of volunteer coaches can make searching less frustrating for the beginner. Volunteers should be both competent computer users and good listeners. Veteran patients who are familiar with the Internet make excellent coaches because they provide a dimension of healthcare experience that others cannot. If a patient is interested in learning how to find health-related Internet information, ensure that the patient receives a demonstration. This may involve explaining terms as well as demonstrating skills. Figure 2-1 lists terms that usually are new to novice Internet users.

Most patients new to the Internet are amazed at the amount of healthcare information that is available on the Web. The fact that patients have Internet access, however, does not mean that they will be able to find the information they want.

How to Find Information on the Internet

Figure 2-2 is a summary of tips about finding information on the Internet. Patients who use the Internet to find cancer information will be looking for resources that will provide information about a specific topic or trying to find a specific Web site that they already know about.

Figure 2-1. Glossary of Internet Terms

Chat. Real-time communication between two users, via computer. After a chat has been initiated, either user can enter text by typing on his or her keyboard; the typed text will appear on the other user's monitor. Most networks and online services offer a chat feature.

Chat room. The Internet "channel" on which a chat takes place.

E-mail. From the term *electronic mail*. E-mail allows one person to send messages to any other person who has a computer that can receive e-mail. In addition, a sender can send the same e-mail to many people at the same time. Having e-mail is a prerequisite to joining a listserv or newsgroup. Sent messages are stored in an electronic mailbox until the recipient retrieves them. The mailbox does not reside on the recipient's computer, so the recipient does not lose messages if his or her computer is not on all the time or continuously hooked up to the telephone line. After reading an e-mail, it can be stored, forwarded to others, or deleted. E-mails can be printed on paper.

Listserv. Also called a mailing list. A listserv is a group of e-mail users interested in participating in an ongoing e-mail discussion devoted to a specific topic. Listservs can be public or private. Some listserv discussions are guided by an expert, or moderator. A listserv manager is responsible for sending the messages to the participants. Sometimes managers screen messages for appropriateness. After you sign up for, or subscribe, to a listserv, you receive, as a separate e-mail, every message that is posted to the group. Receiving dozens of messages each day is common if the listserv is an active one.

Newsgroup. Also called a discussion forum, a newsgroup is a public exchange of information, on the Internet, about a specific topic. Rather than producing a series of individual e-mails, as a listserv does, a newsgroup is a collection of messages, like a bulletin board. Anyone in the world with Internet access can read and post messages in a newsgroup; a participant does not have to subscribe first. One of the most popular collections of newsgroups is Usenet. The Usenet search engine is called DejaNews.

Search engine. A software program that scans Internet pages, looking for a specific term or phrase. (The term is the index word, or keyword, of the search.) Most search engines are available on the Web at no charge. Some search the words, titles, or headings of documents; some search the documents themselves; and others search indexes or directories.

World Wide Web. Also known as www or the Web. The World Wide Web is the "point and click" graphic portion of the Internet. It is made up of millions of pages, thousands of which provide different kinds of cancer information. Each page can contain links (connections from one page to another), allowing a Web user to branch off to another site for more information and then return to the original site.

Figure 2-2. Tips for Finding Information on the Internet

1. Plan the search and choose keywords, or search terms, with care. Take notes to stay organized.

2. Be patient. Although the Internet offers immediate access 24 hours a day, it can be a very busy place. If slowed by a traffic jam of users, try the search some other time. High speed access can facilitate the search. If you are dialing in from home, consider going to the library or Patient Education Center for DSL or cable access.

3. After finding a relevant site, learn how it functions and what kinds of information it offers.

4. Have reasonable expectations. You may not find everything you are looking for on the Internet.

5. If the site offers a list of frequently asked questions (FAQs), read them and the answers. Reading an FAQ list will save a lot of time.

6. If you are part of an online discussion, keep your questions or comments short. Use common sense when sharing information. Do not post anything that should be kept secret, like credit card numbers or passwords.

7. Evaluate the credibility of Internet sources and check information as needed.

A word of caution: A great deal of helpful, reliable information is available on the Internet; the Internet presents a lot of faulty information, too. As you use Web sites, read critically. Question your sources. The most reliable medical information often comes from groups: nonprofit organizations, research facilities, libraries, and government agencies.

Looking for Information on a Specific Topic

Unless you know that the exact URL (Web address) of the Web site will provide the information you want, you will have to perform some kind of search. The three major search tools are search directories, search engines, and metasearch engines. Table 2-1 presents examples of each type.

Search Directories

A search directory is a Web site that most closely represents a brick-and-mortar library in that it offers an organized scheme for finding information. Yahoo, at www.yahoo.com, is a well-known and frequently used search directory. The home page of a search directory lists categories of subjects. The categories and their contents have been assembled by trained professionals who, like librarians, arrange information into a hierarchical, subject-based structure. You can browse each subject area just as you can browse the shelves in a library. Each directory uses a unique categorization scheme and its own method of assigning sites to categories.

A search directory works well in cases in which the needed information is more general in nature and can be easily placed in a single category. Most search directories provide a one-line abstract of a referenced site before linking to that site. These descriptions are very helpful to a user unfamiliar with the subject under investigation.

Most search directories contain a search engine that searches the content of that site only. Most search engines index only the home pages of a Web site. This gives the user fewer results and can be less overwhelming.

Search Engines

A true search engine is a software program that scans Internet pages, looking for a specific term. The term is the index word, or keyword, of the search. In a search for information about chemotherapy, for example, the index word is *chemotherapy.* Narrowing the search is possible by searching for more than one index word or an index phrase. Some search engines search for the keyword in titles or headings only, others search all page content, and yet others search directories. Popular search engines include Google at www.google.com.

Unlike a search directory, which is assembled by humans, a search engine is totally automated. This can be an advantage, in that a search engine can direct the user to sites that discuss the searched-for topic in an incidental way, not as the main subject. Search engines do not discriminate when a word has two meanings, however. A search for the word *pig* could yield information about the farm animal as well as information about pig iron.

Unlike the one-line abstract provided by a search directory, a search engine usually shows the portion of text in which the index word appears. Just by looking at these extracts, which are completely out of context, deciding whether the referenced site will contain the needed information may be difficult.

Metasearch Engines

A metasearch engine searches other search engines. Some metasearch engines let the user specify which service engines to check. For example, the choice could be the three engines that are responding fastest or the three engines best suited to the structure of the search. The home pages of many metasearch engines contain subject categories and look like the home pages of search directories. An example of a metasearch engine is Ask Jeeves at www.ask.com.

Looking for Specific Web Sites

Web sites provide information about cancer, cancer treatments, and the cancer experience. Some sites are government-sponsored. Some are health portals; some are produced for profit, others are nonprofit sites. Others are designed by pharmaceutical or biotechnology companies to

Table 2-1. Examples of Search Directories, Search Engines, and Metasearch Engines

Search Tools	Internet Address
Search directories	
DejaNews	www.google.com/grphp?hl = en
LookSmart	www.LookSmart.com
Yahoo	www.yahoo.com
Search engines	
AltaVista	www.altavista.com
Direct Hit	www.directhit.com
GO.com	infoseek.go.com
Google	www.google.com
Lycos	www.lycos.com
Northern Light	www.northernlight.com
Webcrawler	web.webcrawler.com
Metasearch engines	
Ask Jeeves[a]	www.ask.com
Dogpile[a]	www.dogpile.com
IQ Seek[a]	www.IQseek.com
Ixquick	www.ixquick.com
Mamma[a]	www.Mamma.com
Metacrawler[a]	www.metacrawler.com
qbSearch	www.qbsearch.com
Search.com[a]	www.search.com
Vivisimo	www.vivisimo.com

[a] A metasearch engine that incorporates advertising.

support their product lines, and others are launched by health systems, healthcare facilities, or health insurance companies. Still others are produced by nonprofit professional, activist, or support organizations or individuals who want to network about their experience.

One particular site may offer exactly the information a patient wants. With an overview of the sites available, you may be able to guide a patient directly to the most appropriate site, without using search engines or subject guides. The sections that follow present examples of many types of Web sites.

Sites Sponsored by the National Cancer Institute

The U.S. Congress established the National Cancer Institute (NCI) in 1937 to coordinate national research programs about the causes of cancer and its prevention, detection, diagnosis, treatment, and control. NCI uses the Internet extensively for public education through two sites: the main NCI information site and the Cancer Information Service (CIS) site.

The main NCI information site can be found at **www.cancer.gov**. Those looking for information about the NCI Hospital should use **www.nci.nih.gov**. Simple graphics make this site accessible to almost any browser. The link

Español, at the bottom righthand side of the home page, leads the user to information in Spanish.

Cancer.gov displays a comprehensive menu that offers links to information about topics throughout the cancer continuum: from genetics, prevention, screening, and causes to types of cancer, treatment, and coping. Menu options lead the user to information about NCI research programs and information about clinical trials—finding trials, recent significant trial results, and the like. From the home page, a user can access statistics from NCI's Surveillance, Epidemiology, and End Results Program and data from the U.S. Centers for Disease Control and Prevention. Information about understanding statistics helps a site user interpret statistics correctly. A link to the News Center provides access to NCI press releases. Help in navigating www.cancer.gov is available in the form of frequently asked questions (FAQs) about the site.

The site cancer.gov helps users find non-NCI information by providing a CANCERLIT® search engine. CANCERLIT is a bibliographic database that contains more than 1.5 million citations and abstracts from biomedical journals, proceedings, books, reports, and doctoral theses. The database contains references to cancer literature published from the 1960s to the present and is updated with more than 8,000 entries monthly.

Features of the main NCI site that may be of special interest to patients and healthcare professionals alike are home-page links to information about NCI research programs and research funding and links to the Physician Data Query (PDQ®) database. PDQ is an NCI database that contains the latest peer-reviewed information about cancer treatment, screening, prevention, genetics, supportive care, and clinical trials. In addition, www.cancer.gov offers information about the Partnership Program, an NCI program that helps organizations reach minorities and the medically underserved with information about cancer and cancer treatment.

The CIS site at http://cis.nci.nih.gov. The CIS Web site describes the many services of the CIS, which brings cancer information, in a variety of forms, to the public. The CIS Web site advertises the CIS toll-free telephone number, 800-4-CANCER (22-6237), which will allow a caller to speak with an NCI staff member about cancer risk (including smoking cessation), types of cancer, treatments (including referral to clinical trials), and many other topics. CIS provides a live-messaging information service called LiveHelp. To access LiveHelp, click the LiveHelp link on the CIS home page. In addition, CIS distributes free printed NCI publications by fax and U.S. mail; see the site for details.

Health Portals

Health portals are very large Web sites that are dedicated to health care in general or to providing information about a specific disease (i.e., breast cancer). Health portals offer a wide variety of services besides information in text and graphic form. For example, many offer

online calendars to keep track of clinic appointments, message boards and chat rooms to allow users to interact with each other, live chats with notable health professionals, healthcare news headlines that change daily, audio and video programs, and free e-mail accounts for those who sign up as members.

The cost of membership is not money; it is information. The Web site may ask prospective members for identifying information, such as U.S.-mail address, telephone number, e-mail address, age, income, type of disease and disease status, and relationship to the person who is ill.

Coach patients and families to look for check boxes that give the site permission to share members' information with third parties (i.e., allow them to "opt in" to information sharing) or deny permission (i.e., allow them to "opt out" of information sharing). Ensure that patients and caregivers understand that they have a choice about circulating information about themselves.

Examples of health portals are

- **WebMD, at www.webmd.com.** A product of WebMD Corp., the WebMD site provides comprehensive general information as well as extensive oncology resources.
- **CancerSource, at www.cancersource.com.** Produced by Jones and Bartlett Publishers in partnership with ONS, the site is for oncology professionals and offers frequent live chats with nursing professionals.
- **Medscape, at www.medscape.com**

Sites Sponsored by Pharmaceutical or Biotechnology Companies

Many pharmaceutical and biotechnology companies offer excellent information on their Web sites. Although information typically is labeled as being for patients or professionals, few if any barriers exist that prevent patients from reading material for professionals or vice versa. The Web sites of many pharmaceutical or biotechnology companies offer package inserts, slide presentations, and audio and video programs.

Ensure that patients and families understand that these sites do not necessarily provide a balanced view of treatment options. The sites may be vehicles for direct-to-consumer advertising whose primary purpose is selling specific products.

An example of a site produced by a biotechnology company is The Growth Hormone Site, at http://growthhormone.gene.com. This site is produced by Genentech, Inc. It provides information about the science of growth, growth disorders, and growth hormone therapy. Different sections of the site provide information at levels appropriate for adult patients, young patients, and healthcare professionals.

Note that many of the sites produced by pharmaceutical companies or biotechnology firms do not have a company's name or product name in the site name. The site name itself may not provide a clue to the fact that the publisher is a commercial concern. The suffix .com, however, should alert the user to the fact that the publisher has something to sell.

Sites Produced by Health Systems, Healthcare Facilities, or Insurance Companies

Health systems, healthcare facilities, and insurance companies maintain Web sites to drive business to their hospitals, clinics, programs, and products. If the site user can separate marketing material from real information, these sites can be excellent resources, especially if the user is looking for information about the availability of specific treatments. A site maintained by an NCI-designated Comprehensive Cancer Center, for example, usually provides detailed information about the procedures performed at that center. (Information about NCI's cancer center program and a list of Comprehensive Cancer Centers is available at http://cis.nci.nih.gov/fact/1_2.htm.)

Examples of Web sites in this category are

- **OncoLink, at http://oncolink.org.** A product of the University of Pennsylvania Cancer Center, OncoLink provides comprehensive information about types of cancer, updates on cancer treatments, and news about research advances. The site includes clinical trial information and information about veterinary oncology.
- **MayoClinic.com, at www.mayoclinic.com.** Produced by the Mayo Clinic of Rochester, MN, MayoClinic.com offers information about specific diseases and conditions, drugs, and first aid and self-care. The site also offers various online tools for a site user to self-manage his or her health.
- **The Blue Cross Blue Shield (BC-BS) Web site, at www.bluecrossblueshield.com.** In addition to providing local contact information about regional BC-BS plans, the BC-BS Web site offers links to summaries of reports about high-tech health care; a link to HealthDialog.com, which presents a "product suite" to help patients make treatment decisions; and PersonalPath.com, a means of creating a customized Web page that will provide news relevant to the specific concerns of an individual Internet user.

Sites Produced by Professional Organizations, Advocacy Groups, or Support Groups

Many nursing and medical organizations, in addition to providing information for their members, offer consumer-oriented educational materials to patients and families. The Web site of such an organization may be the primary means of disseminating these materials, or the site may list available printed publications.

Many activist organizations maintain a Web presence to link their members across the world and to provide educational resources. Activist-organization Web sites offer a way for geographically dispersed members to communicate and a way for concerned friends and family members to get involved financially and politically. A patient may find the support of one who has "been there," be-

cause many sites offer e-mail or telephone support as well as listings of support groups in various areas. Some Web sites provide support for patients who have commonly diagnosed cancers; other sites are for patients who have been diagnosed with rare cancers. Patients with a rare cancer may find particular solace from a Web site devoted to their condition because information about the condition may be hard to find. At the same time, such users may be particularly vulnerable to misinformation because relevant written material is so rare and they may be desperate to find a successful treatment. These patients may be so happy to find *any* information that they forget to assess it critically.

The professional, activist, or support groups discussed in the paragraphs that follow maintain Web sites that describe or provide services to patients with cancer.

Alliance for Lung Cancer Advocacy, Support, and Education (ALCASE), at www.alcase.org. ALCASE provides people with lung cancer and their families a variety of services, including toll-free telephone support and information, a newsletter, customized research and resource services, telephone buddies, and support groups. Toll-free telephone: 800-298-2436. E-mail: info@alcase.org

American Association of Sex Educators, Counselors and Therapists (AASECT), at www.aasect.org. AASECT provides names of licensed sexuality counselors and therapists. The Web site provides access to the full text of the *Journal of Sex Education and Therapy,* offers continuing education information for professionals, and highlights current events that include issues of sexuality. E-mail: AASECT@mediaone.net.

American Cancer Society (ACS), at www.cancer.org. The ACS focuses on research and education and has local units throughout the United States and in Puerto Rico. A search engine on the home page provides contact information regarding local ACS units. The units offer public and professional education programs, referral to community resources, and patient and community services. Toll-free telephone: 800-ACS-2345 (227-2345). E-mail: Use the online form on the ACS Web site.

American Pain Society (APS), at www.ampainsoc.org. APS provides a directory of more than 500 specialized pain treatment centers in the United States. Telephone: 847-375-4715. E-mail: info@ampainsoc.org

American Society of Clinical Oncology (ASCO), at www.asco.org. The ASCO site allows users to find an oncologist, buy ASCO publications, and read about cancer-related topics that are in the news. Free abstracts of articles from the *Journal of Clinical Oncology* are available. Telephone: 703-299-0150. E-mail: asco@asco.org

Cancer Care, Inc., at www.cancercare.org. Through professional one-to-one counseling, support groups, educational programs, and telephone contact, Cancer Care provides guidance, information, and referrals to cancer patients and families. Toll-free telephone: 800-813-HOPE (4673). E-mail: info@cancercare.org

Cancerfatigue.org, at www.cancerfatigue.org, a Web site produced by ONS. This site offers, to patients and caregivers, information about fatigue related to cancer treatment. It provides energy-saving techniques and tips for talking to physicians about fatigue. Also available is an online e-mail form that allows a site user to ask an oncology nurse fatigue-related questions. E-mail: webmaster@cancerfatigue.org

Candlelighters Childhood Cancer Foundation (CCCF), at www.candlelighters.org. CCCF provides support, information, and advocacy regarding childhood cancer as well as referrals to local self-help groups. CCCF publishes newsletters, a bibliography, and other materials; replies to requests for information; maintains an ombudsman program relative to insurance concerns; and promotes a long-term survivors network. Other services include bereavement counseling, pain management, and a speaker's bureau. Toll-free telephone: 800-366-2223. E-mail: info@candlelighters.org

Lymphoma Research Foundation (LRF), at www.lymphoma.org. LRF is a nationwide not-for-profit organization dedicated to funding research and providing support and education for those whose lives have been touched by Hodgkin's disease and non-Hodgkin's lymphoma. Education and support services include patient-to-patient telephone networking, educational family forums, support groups, and printed resources. Telephone: 800-235-6848. E-mail: helpline@lymphoma.org

Foundation for Children's Oncology Group (FCOG), at www.nccf.org. FCOG supports a network of childhood cancer programs—at institutions in North America, Australia, and Europe—that conduct laboratory research and provide state-of-the art care to infants, children, and young people with cancer. The foundation, associated with the Children's Oncology Group research organization, also supports education and advocacy in regard to the needs of children with cancer. Toll-free telephone: 800-458-6223. E-mail: info@ConquerKidsCancer.org

Genetic Alliance, at www.geneticalliance.org. This site provides resources and information about support groups for individuals with genetic disorders. Toll-free telephone: 800-336-GENE (4363). E-mail: info@geneticalliance.org

International Myeloma Foundation (IMF), at www.myeloma.org. IMF publishes a newsletter, hosts patient and family seminars and clinical conferences, maintains an information hot line about myeloma and its treatment, and provides printed resources. Toll-free telephone: 800-452-2873. E-mail: TheIMF@myeloma.org

Let's Face It (LFI), at www.faceit.org. To people with facial disfigurements and their families, LFI provides general resources, resources about specific categories of conditions, tools for parents and educators, information about surgery and recovery, and legal resources. Telephone: 360-676-7325. E-mail: letsfaceit@faceit.org

Leukemia & Lymphoma Society (LLS), at www.leukemia.org. LLS's mission is to cure leukemia, lym-

phoma, Hodgkin's disease, and myeloma and to improve patients' and families' quality of life. Chapters throughout the United States offer free counseling groups, financial assistance, grants, professional education, a speakers' bureau, publications, information, and referrals. Toll-free telephone: 800-955-4572. E-mail: Use the online form on the LLS Web site.

National Coalition for Cancer Survivorship (NCCS), at www.advocacy.com. Founded by and for cancer survivors, the NCCS is a national grassroots network of individuals and organizations working on behalf of people with all types of cancer. Its mission is to lead and strengthen the survivorship movement, to empower cancer survivors, and to advocate for policies that benefit cancer survivors' quality of life. The NCCS serves as a clearinghouse for information about survivorship. It encourages the study of survivorship and promotes the development of cancer support activities. Toll-free telephone: 888-650-9127. E-mail: info@cansearch.org

National Hospice and Palliative Care Organization (NHPCO), at www.ho.org. NHPCO is a resource for professionals and volunteers committed to providing service to patients and their families during the end of a life. The organization is committed to improving end-of-life care and expanding access to hospice services. NHPCO's goal is to profoundly enhance the quality of life for the dying and their loved ones. The Web site provides a search engine that provides contact information about local hospice programs. Toll-free telephone: 800-658-8898. E-mail: Use the online form on the NHPCO Web site.

Kidney Cancer Association (KCA), at www.nkca.org. KCA educates the public about kidney cancer and advocates on behalf of patients with kidney cancer by offering information and referrals, drug-trial information, online chats, and a speakers bureau. The organization also provides funding for research. Toll-free telephone: 800-850-9132. E-mail: office@kidneycancerassociation.org

National Lymphedema Network (NLN), at www.lymphnet.org. NLN is a nonprofit organization that provides education and guidance about lymphedema to patients with lymphedema, healthcare professionals, and the general public. Services include referrals, a newsletter, and courses for healthcare professionals and patients. Toll-free telephone: 800-541-3259. E-mail: nln@lymphnet.org

National Ovarian Cancer Coalition (NOCC), at www.ovarian.org. NOCC provides information about ovarian cancer and support groups for patients with ovarian cancer. NOCC also advocates on behalf of individuals with the disease. Toll-free telephone: 888-OVARIAN (682-7426). E-mail: NOCC@ovarian.org

ONS Online, sponsored by Oncology Nursing Society (ONS), at www.ons.org. ONS is an organization of more than 30,000 registered nurses and other healthcare professionals dedicated to excellence in patient care, teaching, research, administration, and education in the field of oncology. ONS Online provides peer-reviewed links, educational events, educational materials and textbooks, and a legislative action center. Telephone: 412-859-6100. E-mail: customer.service@ons.org

Patient Advocate Foundation (PAF), at www.patientadvocate.org. PAF is a nonprofit organization that serves as a liaison between a patient and his or her insurer, employer, and/or creditors to resolve insurance, job discrimination, or debt-crisis matters relative to a health diagnosis. PAF seeks to safeguard patients through effective mediation, ensuring access to care, maintenance of employment, and preservation of financial stability. Toll-free telephone: 800-532-5274. E-mail: help@patientadvocate.org

Support for People With Oral and Head and Neck Cancer (SPOHNC), at www.spohnc.org. SPOHNC is a patient-directed self-help organization that addresses the broad emotional, psychological, and human needs of people with oral and head and neck cancers. SPOHNC offers small-group meetings, patient networking, a nationwide newsletter, and general information for patients and families. Toll-free telephone: 800-377-0928. E-mail: info@spohnc.org

Susan G. Komen Breast Cancer Foundation, at www.komen.org. The foundation is a national volunteer organization working through local chapters and Race for the Cure events across the United States to eradicate breast cancer by advancing research, education, screening, and treatment. Trained volunteers provide information about breast health and answer questions about breast cancer. Toll-free telephone: 800-IM-AWARE (462-9273). E-mail: helpline@komen.org

United Ostomy Association, Inc. (UOA), at www.uoa.org. UOA is a volunteer-based organization dedicated to providing education, information, support, and advocacy for people who have had or will have intestinal or urinary diversions. The group sponsors local chapters that provide mutual support, educational materials, advocacy services, and a quarterly publication. Toll-free telephone: 800-826-0826. E-mail: uoa@deltanet.com

US TOO! International, Inc. (US TOO!), at www.ustoo.org. US TOO! provides prostate cancer survivors and their loved ones with emotional and educational support through an international network of chapters. The organization also provides professional education for those working with prostate cancer survivors, and it publishes a quarterly newsletter. Toll-free telephone: 800-80-US TOO (8-7866). E-mail: ustoo@ustoo.com

Y-ME National Breast Cancer Organization (Y-ME), at www.y-me.org. Y-ME provides information, referral, and emotional support to individuals concerned about or diagnosed with breast cancer. Y-ME offers peer groups, counseling, volunteer matching, educational materials, referrals to community resources, and a detailed self-help manual for starting support groups. It also maintains a prostheses bank for women in financial need. Men can

ask to speak to a male counselor. The Y-ME Web site is available in English and Spanish. Toll-free telephones: 800-221-2141 (English), 800-986-9505 (Spanish). E-mail: help@y-me.org

Yul Brynner Head and Neck Cancer Foundation, Inc., at www.headandneck.org. This organization provides information about head and neck cancer for patients and families; organizes support groups on a national basis; and sponsors Head and Neck Cancer Awareness Week, an annual nationwide campaign designed to increase public awareness and education regarding the causes, prevention, and treatment of head and neck cancer. Telephone: 843-792-6624. E-mail: blakeh@musc.edu

Sites Produced by Individuals

Both individual healthcare professionals and individual patients provide health-related information on the Internet. Just because an individual publishes information on the Internet does not mean that he or she has the credentials to produce quality information or evaluate the information the individual passes along to others. Tell patients to carefully examine a site published by an individual to determine the publisher's qualifications as an information provider. Coach patients to look for privacy and disclosure statements so they will know if information they provide as users will be shared. In addition, patients should be alert for signs that indicate that the publisher has affiliations or has had experiences that bias site content.

Updating a Web site can be expensive and time-consuming. Sites maintained by individuals may not be updated as frequently as larger sites, and they may not have expensive components, such as news feeds. Often, once the patient finishes treatment, he or she does not maintain the site. Nevertheless, many excellent sites are produced by individuals who have personal or professional experience with cancer.

The following cancer-related Web sites were created by individuals.

- **Prostate-Help!,** at www.cooleyville.com/master. Prostate-Help, created by cancer survivor Dan Cooley, is for patients and their loved ones who are fighting prostate cancer. The site offers mailing lists to join, the Patients Helping Patients section, and a section called Physicians Helping Physicians.
- **LymphomaNet,** at www.lymphomainfo.net. Created by Hodgkin's lymphoma survivor Mike Barela, this site offers information about Hodgkin's and non-Hodgkin's lymphoma, information about treatments and life after treatment, lists of support resources and books, and a glossary.
- **CancerGuide,** at http://cancerguide.org. CancerGuide presents readings; tips about researching medical literature; information about the clinical-trial system, understanding statistics, second opinions, and kidney cancer; and a list of resources. The creator of this site is cancer survivor Steve Dunn.

How to Evaluate the Quality of Online Information

The quotation at the beginning of this chapter reported that more than 60 million Americans look for medical information on the Internet each year (Berland et al., 2001). But what exactly are they finding? At best, the quality of healthcare information on the Internet is highly variable. Very little of it undergoes the rigorous peer-review process that academic journals employ. Yet, because it is published on the Internet, many people give online information more weight than they give to the conventional written word. Compounding the problem is the fact that misinformation on the Internet has the potential to reach millions of readers. Berland et al. found that many health Web sites offer incomplete or misleading information and that others often blur the line between content and advertising.

Oncology healthcare professionals can be of great help to patients and families by coaching them how to evaluate the online resources they consult for cancer-related information. To evaluate the credibility of a Web site and the information posted on it,

- Look for disclosure of key information.
- Scrutinize the publisher.
- Determine if the site adheres to guidelines established by independent site-rating organizations.

Look for Disclosure of Key Information

On a credible Web site, the following information should be readily accessible from the home page, or the "about us" page:

- The date the site was last updated
- A financial disclosure statement about funding indicating sources and services donated in kind to produce the site.
- A link to a privacy statement that describes in detail what will be done with information collected.
- A link to a page that describes the qualifications of the information provider (The next section will discuss how to evaluate qualifications.)
- A link to a Webmaster, or technical support person, who can assist the user with technical difficulties.

Scrutinize the Publisher

The first step in scrutinizing the author of the site is to ask the question: Who stands behind the Web site? Is it an individual or an organization? Is the author's name clearly noted in the headers or footers on each page or by means of a distinctive watermark, or background pattern? Credible sites tell the user who published them. Furthermore, a credible site usually provides contact information that allows a site user to communicate with someone on the publisher's staff.

After determining the site publisher, ask if the publisher has the expertise to be publishing in the field to which

the site is devoted. The same question applies to any authors who are credited on the site. Are they recognized experts with appropriate academic or professional credentials?

Then ask why the publisher has gone to the time and expense to launch and maintain a site. To what extent is the site a marketing tool? How does its marketing goal affect content? For example, if the site is published by a healthcare facility that wants to drive business to its programs, it will be unlikely to mention that newer technology is available at the hospital down the street. If the site publisher is an insurance company, it is unlikely to provide a wealth of positive information about a procedure that the company does not cover. If the site accepts advertising, be aware that the advertisers' interests may affect content. Even an individual who publishes a site at his or her own expense and is not selling anything could have a bias that affects content. He or she may feel wronged by some aspect of the healthcare system, for example, and site content in regard to that aspect may be subtly or overtly negative. Avoid anonymous information at all cost.

Determine if the Site Adheres to Independent Site-Rating Guidelines

Established guidelines are emerging for evaluating online healthcare information, but using these guidelines to develop Web-site content is still voluntary. The Health on the Net Foundation (HON), Mitretek Systems, and ONS are a few of the organizations that have developed site-evaluation guidelines.

Health on the Net Foundation Guidelines

The mission of HON, a Swiss nonprofit organization, is to guide nonmedical Internet users and medical practitioners to useful and reliable online medical and health information. The foundation does this by evaluating sites according to criteria in the HON Code of Conduct (HONcode). A site that complies with the guidelines may display the HONcode logo. The code is based on eight principles.

- **Authority.** Qualified professionals provide the information.
- **Complementarity.** The information the site provides is designed to support, not replace, the relationship between a patient and his or her physician.
- **Confidentiality.** The site publisher keeps information about site visitors and patients confidential.
- **Attribution.** The site credits sources and shows when the site was last updated.
- **Justifiability.** The site supports claims by supplying balanced evidence.
- **Transparency of authorship.** The Web design displays information in a way that is easy to understand, and the site provides contact information.
- **Transparency of sponsorship.** The publisher identifies commercial and noncommercial organizations that have supplied funding, services, or materials to the site.
- **Honesty in advertising and editorial policy.** The site displays its advertising policy, and advertising is clearly delineated from editorial content.

Because no practical way to police placement of the logo exists, HON relies on the honesty of Web developers to ensure that the logo appears only on sites that have earned it ("Policing the HONcode," 2000). The foundation also depends on the public to notify it if the HONcode logo is used on a site that does not meet the code. If an offending site ignores written requests to remove the logo, the foundation uses a software program to remove it.

Information Quality Tool From Mitretek Systems

Mitretek Systems is a Virginia-based nonprofit information technology and environmental management organization. It established the Health Information Technology Institute (HITI) to apply technology solutions to improve the efficiency and capability of healthcare delivery. In 1996, the institute formed a group to compose guidelines to help the public evaluate the quality of health information on the Internet. Two years later, the result of the group's work, the Information Quality (IQ) Tool, became available on the Internet at http://hitiweb.mitretek.org/iq. The IQ Tool is still a valuable yardstick for evaluating health-information Web sites.

The IQ Tool consists of three lists of questions. The list an evaluator chooses depends on whether he or she is evaluating a Web site of general interest or a site that is selling a product or service. The criteria in each list are similar to those that form the basis of the HONcode.

From the IQ Tool, the evaluator opens the Web site he or she intends to critique. Within a frame, the IQ Tool questions are visible; the evaluator can see the Web site and the IQ Tool questions simultaneously. The evaluator assesses Web content by answering the IQ Tool questions and recording the answers by clicking the appropriate spot in the IQ frame. After completing the questions, the IQ Tool scores the answers automatically, providing a quantitative measure of the Web site's credibility. By reading an answer sheet, the evaluator can read about the significance of the chosen answers.

The IQ Tool is a systematic and convenient way to evaluate health and medical information on the Internet. An evaluator's computer must support frames to use the tool as it was designed, however. Those who cannot use frames can print the list of questions and score their answers manually.

ONS Online's Web Site Guidelines

The Editorial Board of the ONS Web site, ONS Online, evaluates site credibility by assessing
- Credibility of the information provider or author
- Disclosure of sponsorship
- Privacy of user-data collected.

The board also uses these criteria to evaluate all the sites to which the ONS site links.

References

Berland, G.K., Elliott, M.N., Morales, L.S., Algazy, J.I., Kravitz, R.L., & Broder, M.S., et al. (2001). Health information on the Internet: Accessibility, quality, and readability in English and Spanish, *JAMA, 285,* 2612–2621.

Fox, S., & Rainie, L. (2000). *The online healthcare revolution: How the Web helps Americans take better care of themselves.* Washington, DC: Pew Charitable Trusts.

Goldsmith, J. (2000). How will the Internet change our health system? *Health Affairs, 19,* 148–156.

Health on the Net Foundation. (2000). *Policing the HONcode.* (2000). Retrieved August 14, 2001, from http://www.hon.ch/HONcode/policy.html

Rainie, L., & Packel, D. (2001). *More online, doing more: 16 million newcomers gain Internet access in the last half of 2000 as women, minorities, and families with modest incomes continue to surge online.* Washington, DC: Pew Internet & American Life Project.

U.S. Department of Commerce. (2002). *A nation online: How Americans are expanding their use of the Internet.* Washington, DC: Author.

Chapter 3:
Communication Skills

Judy Lyter, RN, MS, NCC, LPC

Chapter Goal

The goal of this chapter is to provide oncology professionals with the knowledge and skills they need to help patients, caregivers, and other healthcare professionals to become effective communicators.

Facilitating Communication: The Healthcare Professional's Role

In February 2002, U.S. Senator Dianne Feinstein (D-CA) introduced the National Cancer Act of 2002 (S. 1976), legislation to change the model of cancer care and increase funding for cancer research and prevention. Among the most significant aspects of the National Cancer Act is the requirement that public and private health insurance plans pay doctors, preferably oncologists, to assume a manager's role in the care of patients with cancer. Such a doctor would be a "cancer quarterback," coordinating care and helping each patient to make decisions from diagnosis through treatment. In proposing the cancer quarterback concept, the National Cancer Act recognizes the need to build patient advocacy into the model of cancer care. The concept arose in reaction to the increasing complexity of modern health care, which often involves conflicting instructions from multiple healthcare providers, frustrating insurance systems, concerns about employment, and information overload. Another stimulus for the cancer quarterback concept is the realization that patients are happier, and so tend to do better, when their views are heard and respected.

This realization is not new. Shields (1984) explained how effective communication leads to and improves the patient's autonomy, decreasing the dependence that the role of patient sometimes creates. Shields maintained that communication blocks that result in unexpressed feelings, for example, can be more debilitating to the patient than the cancer itself. Potentially harmful behaviors, he noted, include keeping silent about important issues, including feelings; giving false assurances; and hovering by the family.

In addition to providing the information that patients, families, and caregivers need to understand the patients' disease and provide care, a healthcare professional should

- **Provide patients, cancer survivors, families, and caregivers with information about basic communi-

cation skills to promote self-advocacy.** By helping people self-advocate, the oncology professional ensures that all parties, from the "professional side" and the "patient side," are active partners in the healthcare team (a concept that has not always been a part of patient-doctor relationships). Two printed resources that may be helpful in promoting effective communication skills are *Listen With Your Heart: Talking With the Cancer Patient* (American Cancer Society, 1996) and *Teamwork: The Cancer Patient's Guide to Talking With Your Doctor* (Clark, 1998).

- **Facilitate inclusive communication.** Waitzkin (1984) noted that patients and caregivers strongly dislike the "high control" style of communication that results when doctors feel compelled to ask all the questions. Communication must be inclusive, and healthcare professionals must pave the path for it by inviting and encouraging patients' participation instead of trying to control their input.

- **Be aware of nonverbal communication in their interactions with members of the healthcare team.** Waitzkin (1984) noted that the nonverbal communication of healthcare professionals, patients, and cancer survivors is as important as their verbal communication. His study demonstrated that patients and caregivers respond better to physicians who can "decode" body language. In addition, he demonstrated that decoding skills could be taught.

Special challenges that healthcare professionals face in fulfilling communication-related responsibilities include

- **Providing adequate support to the caregiver.** Most caregivers find themselves in the position of taking on new roles that overwhelm them. In some cases, a caregiver must advocate for a patient who is not physically or mentally able to self-advocate. What is more, during a patient's health crisis, the caregiver may overlook his or her own support needs or consider the expression of personal feelings or needs selfish. Health-

care professionals must be diligent in prompting the caregiver for feedback about his or her own condition; noticing the caregiver's mood, stamina, and coping effectiveness; and ensuring caregiver support when needed.

- **Communicating effectively after delivering bad news.** In many cases, hearing ceases after bad news is delivered. Anything said after the delivery of bad news usually goes unheard because the listener is struggling with the emotional impact of the news or trying to determine how the bad news will affect others. For example, an oncology professional who tries to communicate a detailed plan of care immediately after telling the patient that he or she has cancer will probably communicate very little. The patient needs time to process information. The professional must help patients and families understand that asking the healthcare team to readdress and reinforce information at subsequent appointments is perfectly acceptable and encouraged. Do not assume that a family member or friend who comes with the patient as "an extra pair of ears" will be any more retentive than the patient. This person is likely to be just as shaken by the bad news as the patient and just as likely to reach information overload. (At later appointments, when discussing details is more appropriate, the patient may find taking notes or using a portable tape machine to record discussions to be helpful.)

The references listed at the end of this chapter are resources that can help healthcare professionals to improve their own communication skills as well as teach self-advocacy to patients, families, and caregivers.

Five Basic Communication Skills

This module will discuss communication in terms of five basic skills. The goal of learning these skills is to improve others' understanding of the speaker's view (the message) as well as the speaker's understanding of the feedback from the listener (the reply).

Assertiveness

In educating the patient and caregiver about assertive communication, begin by explaining the difference between *assertive* and *aggressive*. In assertive communication, the speaker makes a statement. In aggressive communication, the speaker does more than make a statement; he or she tries to dominate discussion, disregarding the listener's rights and dignity. Assure patients and caregivers that, in the healthcare environment, everyone has the right to be assertive, but no one has the right to be aggressive.

Patients may be reluctant to have an open and honest discussion with their healthcare professionals because they fear being perceived as aggressive. They think their "stupid questions" take up the professionals' "valuable time" and that professionals will think that the patients are bothersome, pushy, and asking for more than their

fair share of attention. Even worse, some patients may think that, if they upset or question the healthcare professional, especially the doctor, their care will suffer.

As a healthcare professional, it is your job to help. We are here to serve them. By stating their needs—whether the need for a repeated explanation or more time to process information—patients are not seeking to dominate anyone and they are not insulting anyone's dignity; they are just telling the professional how to best serve them. By being assertive, patients can, in many cases, help healthcare professionals be more efficient because the professionals do not have to spend time guessing what the patients need.

To encourage patients to speak up, show them the patients' bills of rights for the institution. This document illustrates for the patient that the institution policy not only supports assertive communication but encourages it. It mandates that no action on the patient's part will result in being singled out or receiving poor care. Healthcare professionals can use the following measures to help a patient to deal with the fear of substandard care at the time of entry into the system.

- Review patient's bill of rights.
- Orient patient/family to the system.
- Introduce key staff.
- Share the business end of someone's authority to call if needed.

Literally, life or death hangs in the balance. Perhaps the most important time to encourage assertive communication is when discussing do not resuscitate orders. Constancy in your role as advocate for patients will help patients understand that they have much more than a patient's bill of rights to protect them: They have *you*. You would not permit substandard care.

Encourage patients to take an active role in their care and in the planning of that care. Encourage them to speak up, request explanations, and let the healthcare team know when they need more time to process information.

The Use of "I Messages"

An I message is a statement that allows the speaker to address a problem the speaker thinks the listener is causing, without putting the listener on the defensive (Shields, 1984). The message consists of three components:

- **The "I feel" part.** In this part of the statement, the speaker tells how he or she feels about a problem the speaker thinks the listener causes.
- **The "when," or behavior, part.** In the "when" component, the speaker tells what the listener does that causes the problem.
- **The "I want" part.** The speaker tells the listener what the listener can do to resolve the problem.

Many I messages include a fourth component: the "because" section, in which the speaker explains why the listener's behavior causes problems. The four components can be in any order.

Shields (1984) asserted that I messages can facilitate communication without putting recipients on the defen-

sive. The author pointed out that communication efforts within a family can improve patient autonomy and decrease a patient's feelings of helplessness.

This example shows the three basic components and a because section.

> I feel angry **when** our sessions are cut short, **because** too much information has to be crammed into the time we have together. I **want** to meet again on Tuesday, please, and make sure that future sessions always are at least one hour long.

The power of the I message lies in its ability to defuse conflict by stating "I feel" rather than "you are." An "I feel" statement is hard to argue with because who knows the speaker's feelings better than the speaker? A listener almost always will construe an unpraising "you are" statement as an attack. Compare the previous example to this "you are" assertion.

> You are rude for allowing interruptions during the time we had set aside to discuss my care plan. You must be crazy to think anybody could talk about everything we had to discuss in the time you allowed. How do you expect me to do what I'm supposed to do based on that ridiculously short meeting?

In which discussion would you choose to participate, the "I feel" discussion or the "you are" discussion? Rather than blocking progress with a barrier of bad feeling, an I message can be the doorway to constructive change.

Shields (1984) suggested that one way for a speaker to enhance the effect of an I message is to imply that some action, inaction, or characteristic of the speaker may play a role in the issue being addressed. For example, following Shields' suggestion, a speaker might expand the sample message so it becomes the following.

> I feel angry when our sessions are cut short because too much information has to be crammed into the time we have together. I just can't absorb that much material in 30 minutes. I would like to meet again on Tuesday and make sure that future sessions always are at least one hour long.

The statement about the speaker's ability to absorb is accurate—the speaker was not able to grasp all the material; maybe nobody could. The key is the self-effacing way in which the fact is stated. The suggestion that the speaker's "slow absorption" may have contributed to the ineffective meeting further removes the statement from the realm of the personal attack. It allows the listener to move past what has happened to the point of accepting the solution the speaker proposes.

Active Listening

Listening with undivided attention; making eye contact, when doing so is culturally appropriate; and nodding and using facial expressions and other cues to demonstrate understanding are indicative of active listening. The second part of being an active listener is summarizing the speaker's message as a way of checking that the listener was heard and understood correctly. Begin the summary with a phrase such as "What I hear you saying is . . ." or "Do I understand you correctly as saying that . . . ". In addition to highlighting points that the professional did not perceive correctly, using a checking phrase helps the patient see if he or she left out something important. Skipping important information is easy when trying to tell a story quickly.

Active listening skills are extremely valuable for healthcare professionals because so much time is spent soliciting and recording information from patients. Active listening helps to ensure that the professional gets the full story and records it accurately. Furthermore, the ability of a patient to trust a professional is based on that patient's perception of being heard.

Awareness of Nonverbal Communication

Body language, or communication by means of physical expression and movement, can speak volumes. If a healthcare professional looks at his or her watch repeatedly during a discussion or listens with an expression that conveys boredom, the patient is unlikely to believe assurances about the healthcare professional being interested in the patient's point of view. To communicate with credibility, the message of the spoken word and the message of the body must match.

Help patients understand that maintaining consistent verbal and nonverbal messages is important to their credibility as communicators. Consider this example involving a patient and a family member: The family member agrees to provide care for a certain period but slams the door loudly when leaving the room. The patient could surmise that the family member is angry about having to provide care and does not really want to do it. Although the verbal message was one of agreement and support; the nonverbal message was of disagreement and nonsupport. Here the nonverbal behavior clearly undermined the verbal message.

Expression of Feelings

Open, honest, and trusting relationships include expressions about feelings. Mrs. R. says, for example, "Sometimes I feel so helpless. I just want to make my husband's pain go away." As Mrs. R. speaks, tears roll down her cheeks. Mrs. R. has conveyed her feelings in verbal and nonverbal ways. The intensity of her feeling helps the healthcare team and the patient to understand the impact of circumstances on Mrs. R. By expressing her feelings, Mrs. R. helps everyone understand the extent of the support she needs and how quickly she needs it.

Encourage patients to express their feelings as they communicate with healthcare professionals. Help them to understand that these feelings provide important clues about

how things are going. Assure them that healthcare professionals are interested in their emotional health and that they will give them the time and support needed to express their feelings.

A Scenario of Effective Communication

The scenario that follows is a dialog that illustrates the effective use of the five communication skills. It is an example that shows the impact the skills can have on a patient, a caregiver, and members of the healthcare team.

Introduction to the Scenario

Mrs. T. and her daughter, Karen, are waiting in the oncologist's office for her pretreatment appointment. Mrs. T is feeling "pretty good" today, but she has not had much energy since her last treatment. On the drive over to the appointment, Karen suggested to her mother that she might benefit by discussing her ongoing battle with fatigue with her doctor.

The Scenario: Karen and Her Mother

Karen: "Mom, I feel so helpless when I see you as tired as you were feeling this week. I hope you're going to tell the oncologist how tired you've been since your last treatment." ·

Mrs. T.: I'm feeling a lot better now. I don't want to stop my treatments. We'll see.

Karen: But you've barely been able to get around, let alone do anything else. You have not been working in the garden at all and I know you love that. Maybe they'll be able to give you something for fatigue, without your having to stop your treatments. I am afraid if you don't say anything, it might just get worse.

Mrs. T.: I'm sorry you've had to help me these past few weeks. I thought you didn't mind.

Karen: I love you and I want to help you as much as I can. I didn't mean you should discuss being tired because I don't want to help you. I think you should discuss your fatigue so that you'll be able to do the things you want to do. [Karen gently touches her mother's arm.] Maybe you'd feel more comfortable talking to the nurse about it.

[Sue, the oncology nurse, enters.]

Sue: Mrs. T., will you come into the exam room, please? [Karen stays in the waiting room while Sue and Mrs. T. go into the examining room. Mrs. T. addresses Sue.]

Mrs. T.: My daughter thinks I should talk to you about how tired I have been since my last treatment. I know it's to be expected. But, to keep her happy, I'm telling you.

[Sue is called away. Mrs. T. puts on a gown, then Karen joins her mother in the examining room.]

Karen: Did you tell the nurse how tired you've been, Mom?

Mrs. T.: Yes, I told her, but she was called away.

[Sue and Brenda, the advanced practice oncology nurse, enter.]

Brenda: Sue told me that you are very tired with this cycle. I'm really glad you told us. It is very normal to feel tired. As a matter of fact, fatigue is one of the most common side effects of chemotherapy. It doesn't mean we have to stop the treatment. There are some things we can do for fatigue, and we can talk about ways to conserve your energy and manage your fatigue.

Mrs. T.: [A little teary.] I was so afraid you would say you had to stop my treatment or that the reason I was so tired was that the cancer was back. Tell me more about what I can do. I'll try anything to feel better and still be able to continue my treatments.

[Later, as Mrs. T. and Karen are leaving the office:]

Mrs. T.: I'm glad you suggested that I talk to the nurse about how tired I was. At first, I thought you were tired of helping me, and I was hurt; I was afraid that if I complained, the doctor would stop my treatments. I feel so much better already. Now maybe I'll be able to enjoy the holiday more.

Analysis of the Scenario

This conversation could have created a real distance between Karen and her mom, if Karen had not used effective communication skills. Initially, she encouraged her mother to be assertive about the fatigue she was feeling. Her mother misconstrued this to mean that Karen did not want to help her. Karen used an I message to demonstrate that she was concerned. She gently touched her mother's arm (nonverbal reinforcement of the verbal message). As a result, Mrs. T. was able to express her feelings and communicate her concerns with the oncology professionals. They helped with her symptoms and dispelled her fear of the treatments being discontinued.

References

American Cancer Society. (1996). *Listen with your heart: Talking with the cancer patient.* Atlanta: Author.

Clark, E. (1998). *Teamwork: The cancer patient's guide to talking with your doctor.* Silver Spring, MD: National Coalition for Cancer Survivorship.

Shields, P. (1984). Communication: A supportive bridge between cancer patient, family, and health care staff. *Nursing Forum, 21*(1), 31–36.

Waitzkin, H. (1984). Doctor-patient communication, clinical implications of social scientific research. *JAMA, 252,* 2441–2446.

Chapter 4:
Decision Making

Eva D. Smith, RN, PhD, FAAN

Chapter Goal

The goal of this chapter is to describe the types of decisions that a diagnosis of cancer necessitates, illustrate the various processes that people use most often to reach decisions, and show how healthcar professionals can provide support throughout the decision-making process.

The Decisions Cancer Necessitates

Decision making is part of everyday actions and activities. For most of us, the decision-making process usually is dynamic and unconscious. Decisions relating to cancer, however, should be conscious and deliberate because they will affect the patient's quality of life and will have significant implications for his or her career, family, and treatment outcome.

Deliberate decision making is especially difficult after receiving a diagnosis of cancer. The diagnosis breaks the shield of feeling safe, leaving anxiety and fear (Harpham, 1994). People with newly diagnosed cancer often feel out of control. Cancer is not a minor medical condition like a headache that can be eliminated with a simple treatment like a pill. No alternative will erase the present reality of cancer cells in the body. Rather than being in the usual position of control, the patient probably feels controlled by experts who are in charge of fine-tuning the diagnosis and planning treatment.

Some of the decisions patients with cancer must make are

- **Ensuring that the diagnosis is correct.** After diagnosis, the patient probably asks him- or herself: Should I seek a second or third opinion? Can I afford more opinions? If so, which doctor will I consult? The first physician available in my managed care plan? Or the doctor with the reputation for being the most competent? If I wait, will the cancer spread rapidly?
- **Selecting high-quality treatment that is appropriate, acceptable, and convenient.** After receiving a diagnosis of cancer, a patient is likely to say "I will leave all the decisions to my doctor, who knows best." In the short term, that attitude may seem the wisest, because the doctor is the expert, and it may be the easiest, because it involves little immediate effort on the patient's part. But consider this: The patient alone will live with the effects of the decisions. These critical decisions will determine, realistically speaking, the shape of the patient's life in the foreseeable future. The patient has a stake not just in choosing the treatment that will produce a desirable medical outcome but also in choosing the treatment that will be the least disruptive to the patient and his or her family.

The decisions do not stop when treatment ends. As people are cured or living longer with cancer, a host of survivor issues have evolved. Some of the decisions cancer survivors must make relate to

- Participating in future cancer prevention and early-detection activities
- Making lifestyle changes, such as quitting smoking; changing the diet to focus on low-fat, high-fiber foods; and exercising regularly.

In studying the decision-making patterns of patients with cancer or their caregivers, Hinds et al. (1997) described the most difficult treatment-related decisions that parents of pediatric patients with cancer encounter and the factors that influence the parents' decision making. Patients reported 15 types of difficult decisions, the majority of which were made late in the course of treatment. Similar factors affected the decision making of parents and healthcare professionals, but the two groups differed in the importance they assigned to each factor. Parents rated recommendations from healthcare professionals as the most important factor. Healthcare professionals rated discussion with the family about the patient as most important to them.

Guidelines for Decision Making

As an oncology professional, you can support your patients by sharing with them two guidelines for decision making. Encourage your patients to

- **Make decisions that help to retain personal identity.** Suppose a patient is a mother, a wife, an employee, and

a volunteer in the community. Ask the patient to prioritize the roles according to which is most important to her. Then encourage the patient to make decisions that help her to retain the roles she finds most important *and* allow her to fit treatments into her daily schedule.

- **Make decisions that maximize the patients' convenience.** A patient may be too quick to say, "I will do whatever is necessary. I will arrange child care, family, work, and other things around my treatment schedule." Encourage the patient to take the time to gather information, consider, and negotiate. Is this a time for a family conference in which extended family members work out a plan of action that involves everyone? What is the schedule that will be least stressful for all? Remind the patient that, at this point, family life can be like a game of dominos. A change in one role within the family may cause the dominos to come tumbling down. Help the patient decide on the treatment plan that can be implemented with the least amount of stress.

Approaches to Decision Making

Decision making is the process of choosing one alternative over another. Understanding the decision-making process as it relates to health care is of interest to healthcare providers, financers, and policy makers because changes in healthcare decisions could change the need for treatment, treatment length, treatment outcome, and cancer survivors' quality of life. Some researchers have focused on identifying decision-making processes; others have examined decision-making styles.

Approaches Defined by Lewis, Corcoran-Perry, Narayan, and Lally

Lewis, Corcoran-Perry, Narayan, and Lally (1999) studied how women make decisions about having mammograms. They identified three different approaches: thoughtful consideration, cursory consideration, and little or no consideration.

In the thoughtful consideration approach, women included multiple factors in making a decision. The researchers defined cursory consideration as decision making characterized by the inconsistent use of information. In the approach involving little or no consideration, the researchers found no evidence of the women using any information in making decisions.

The Decisional Balance Approach

Another approach to decision making is called decisional balance (Prochaska et al., 1994). In this approach, the decision maker weighs the pros (the benefits) and cons (the costs) of changing a behavior or carrying out an action. Using this approach, a cancer survivor may weigh the pros and cons of having a modified mastectomy instead of a lumpectomy. If the pros for the mastectomy outweigh the cons, the person may decide to have the

mastectomy. On the other hand, if the cons outweigh the pros, the lumpectomy may be selected.

The Expectancy Value Approach

Another approach, the expectancy value approach (Stanton et al., 1998), is similar to the decisional balance approach in that it includes consideration of pros and cons. The difference between the two approaches is that the decisional balance approach means weighing issues as they are; the expectancy value approach involves considering the pros and cons of issues according to the best estimate of how they will be. According to this theory, the choice a person selects is based on his or her estimation that an action or condition will occur (expectation) and the importance (value) of the consequence.

Stanton et al. (1998) recounted a longitudinal study that monitored women with breast cancer from diagnosis through one year and tested constructs of the subjective expected utility theory in regard to ability to predict patients' choices about surgical treatment as well as patients' psychological distress and well-being over time. Women's positive expectancies regarding the consequences of treatment generally were sustained in positive perceptions of outcome in several areas (i.e., likelihood of cancer cure or recurrence, likelihood of additional treatment, partner support for options, attractiveness to partner). Expectancy disconfirmations and value discrepancies concerning particular treatment consequences calculated from the point of decision making to three months later were able to predict psychological adjustment at three months and one year after diagnosis.

Decision-Making Styles

The decision-making approaches described in the previous section relate to the steps a patient takes or does not take to reach a decision. The decision-making styles this section will discuss characterize the autonomy with which the patient carries out the steps. The three styles of decision making used most frequently are

- **Dependent and deferred decision making.** A person allows others to make decisions for him or her. This may be due to cultural practices or a preference for noninvolvement.
- **Collaborative decision making.** A person makes a decision about his or her health after consulting with others.
- **Independent decision making.** A person chooses to make decisions independently, without incorporating recommendations from providers or others.

Keep in mind that an approach or style is neither right nor wrong; each is just a preference. The outcomes achieved through different styles and approaches may be different.

Sometimes decision-making style is situational. For example, in a noncrisis situation, a person may be able to make a decision rationally, using a collaborative style and a decisional balance approach (Hinds et al., 1997). During a crisis situation, the same person may need assis-

tance from the provider to make a rational, balanced decision.

The ability to make a rational decision is based on having information about the situation and the resources with which to understand the information.

Decision-Making Scenarios

The eight scenarios that follow involve issues that most patients with concerns about cancer face. The scenarios use a patient's words or a dialog to illustrate various decision-making approaches and styles. The comment after each scenario provides insight for the oncology professional.

Scenario 1: Rachel's Dependent Decision Making

Rachel: In my culture, the male spouse or oldest male in the family makes decisions for the family. Joshua, my husband, asked the doctors many questions. He gathered the adult members of our extended family for a crisis meeting on the evening I received confirmation of my diagnosis. He asked his 24-year-old niece (an oncology nurse) to bring information she secured from the Internet about stage II infiltrating ductal breast carcinoma and breast cancer treatments. My husband began the meeting by explaining what the doctors had stated about my diagnosis and listing the choices we were given for treatment. He then asked his niece to distribute and discuss the information about breast cancer and breast cancer treatments. My husband asked her to clarify several points during her presentation of the information. He then told the group his choice for treatment: surgery combined with chemotherapy and radiation therapy. He thinks the combination of therapies would have a greater probability than surgery alone of destroying all cancer cells and preventing cancer recurrence. He then discussed with the group when I would receive each treatment and what help our family needed. The extended family agreed with his decisions. We made plans for me to work part-time and for my husband's two sisters to care for our six- and nine-year-old children. The plans also included Joshua and I having dinner with the children every day and our nuclear family gathering at least once a week. Joshua will arrange his work schedule so he can accompany me to therapy. I am so relieved that all of these people care so much about me.

Comments About Scenario 1

In Scenario 1, Joshua has been very deliberate in acquiring information from Rachel's doctors and the Internet. He also was deliberate in analyzing Rachel's and the family's needs. If Joshua, on the other hand, had made a decision hastily, without additional information or questions, he would have used the little or no consideration approach. Note Rachel's acknowledgment of her passive role in the decision-making process. She is aware that her culture mandates dependence on her part, and she does not seem to object.

Scenario 2: Jan's Decisional Balance Approach to Lifestyle Choices

Jan: I am 36 years old. I had my baseline mammogram this year—four years ahead of most people's screening schedule. Since my mother, grandmother, and two aunts all had breast cancer, I know I am at high risk for the disease. I am careful about my fat and fiber intake, and I exercise daily. I refused to use birth control pills, even though my doctor told me that they're the most reliable method of preventing pregnancy. (I'm using another birth control method instead.) I believe that, if I am proactive, I can beat this thing and not develop breast cancer.

Comments About Scenario 2

Jan is weighing the pros and cons of various lifestyle choices against what she believes to be her high risk for breast cancer. If, for some reason, Jan learned that pregnancy presented a greater risk to her than breast cancer, then the decisional balance approach might cause her to revisit her self-imposed ban on birth control pills. Note, however, that Jan does not mention anything about having undergone genetic testing and counseling. Is she really at higher than average risk for breast cancer? Deciding whether to undergo genetic testing could add a whole new layer of pros and cons to Jan's decisional balance approach to decision making. For example, for Jan, is the benefit of knowing for sure if she has inherited a cancer-predisposition gene worth the cost of her insurance company finding out about a possibly positive result? If Jan decides to undergo testing, the team that helps Jan interpret her genetic test results should help her put the results in perspective. They should tell her, for example, that many women who develop breast cancer do not have significant risk factors.

Scenario 3: Mr. J. Applies the Expectancy Value Theory

Mr. J.: Well, Doctor, I have thought about my choices: having surgery to remove my prostate or just observing to see how fast the cancer will grow. With surgery, there is a great probability that I will become impotent. On the other hand, at my age, the cancer may grow very slowly, though I will continue to have problems getting my urine started. So what? I have plenty of time to spend in the bathroom getting my urine started. I still like to visit pretty women. My choice is to wait and see, without surgery.

Comments About Scenario 3

Mr. J. expects that surgery will cause him to have problems with impotence that will interfere with his quality of life. He thinks that his cancer will grow very slowly with-

out surgery. Therefore, he decides not to have surgery at this time, to protect his quality of life.

Scenarios 4–5: Jane and William Use Thoughtful Consideration

Jane: I elected to have my chemotherapy on Thursday, in the late evening. I can work on Thursdays and go to my doctor's office from work. And since fatigue for me is worse on the second and third days after treatment, I can work on Friday in the office or at home and have Saturday and Sunday as rest days.

William: I am glad my lung cancer was diagnosed early, when it was possible to remove all the cancerous cells. I decided to accept radiation and chemotherapy as adjuvant therapy. Because I live alone and do not want to trouble my adult children and family members with my health problem, I decided to have my adjuvant therapies on Saturday mornings so I can spend as much time in the office as possible. In addition, I will work at home frequently, especially when my blood counts are low and when I am most vulnerable to infections.

Comments About Scenarios 4–5

Even though Jane and William used the same method to arrive at their decisions about a treatment schedule, each person's schedule is different. Both patients carefully considered their personal situations and reactions to therapy in developing a workable plan of care.

Scenario 6: Jeannine's Independent Decision About Level of Activity

Jeannine: It is amazing what a difference a few days make in your life. Exactly one month ago, I walked across the stage and received my MBA. Two days later, I was in Germany for a much-needed vacation. Then I got sick. Twelve days later, I am back in the United States and in my doctor's office. After the doctor examined me and drew some blood, I went home to sleep for the weekend. Fifteen hours later, a telephone call told me to be admitted to the hospital for additional tests. I still cannot believe that, six hours later, I was told I have acute leukemia.

I thought I was sick before the chemotherapy, but that was nothing compared to my sickness related to chemotherapy treatment.

As I stand here and look out over this city and lake, I see beauty I have never seen before. When I get out of this hospital, I am going to ride slowly throughout the city. I want to see and fully appreciate every inch of it.

Comments About Scenario 6

While Jeannine was at home before her next cycle of chemotherapy, she traveled extensively, visiting and appreciating various sites and museums. She traveled so extensively, against the advice of her family, that they called her Madame Butterfly. Jeannine has lived in the city of her birth all her 27 years, but only after her diagnosis of leukemia does she believe she is really seeing it. Now she views life with much greater appreciation.

Scenario 7: Kathy's Independent Collaborative Decision About Activity

Kathy: My family keeps telling me I am too busy and that I should resign from some of my organizations and activities. They are so afraid that I will get too overloaded with activities and not get sufficient rest. They may not be right. However, I have decided to live as if each day is my first day and my last day. There is no guarantee that, if I slow down, I will not have a recurrence of cancer. Nor is there any assurance that, if I am as busy as a bee, I will get a recurrence. So I will just live and enjoy doing the things I want to do. I am aware that I need to balance things a little more.

Comments About Scenario 7

Kathy has made an independent decision about maintaining her level of activity. At the same time, she is willing to concede that her family is right about her need to conserve her strength. In such a situation, a nurse's role might be to support Kathy by suggesting ways she could be more efficient. Kathy might decide to change the amount of housework she does, alter her schedule so she has to travel less, or accept more help from family. The nurse might also suggest quantitative measures that will help Kathy decide if she is indeed trying to do too much.

Scenario 8: A Collaborative Decision to Skip an Appointment

Dave: Hi, Jill. I'm home. Are you ready to go to your appointment?

Jill: I'm not going to that appointment today. If I see another doctor, I'll just burst.

Dave: Honey, we have to go. Don't you remember? Your doctor said follow-up care is necessary for the rest of your life. I can understand that you're tired. But you just completed your last radiation treatment, and the doctor needs to check your skin and. . . . Well, if you don't keep your follow-up appointments, how can we tell if the cancer comes back?

Jill: I don't care. I'm not moving today. Period!

Dave: But Jill! What are we going to do? [Sigh.] I'll call your doctor. [Dave calls the doctor. Afterward, he speaks again with Jill.] I had a wonderful conversation with your doctor. She asked questions about your skin and energy. I told her you are doing fine except being stubborn. She says that's OK. She said to take a week off and enjoy yourself. Do something for yourself and your spirits. She'll see you next Wednesday. I have a great idea. Let's take a train to New York. We can have dinner, see a play, and be

back in time for your appointment on Wednesday. What do you think?

Jill: Thanks, Dave! New York sounds great if I don't have to do anything today. Could you make reservations for Friday?

Comments About Scenario 8

Jill's spouse and doctor are very understanding and supportive. Although Dave was frustrated with Jill's stubbornness and worried about the consequences it could have, the conversation with the doctor allayed his fears and supported both Jill and him. The doctor's support helped Dave and Jill focus on optimal spiritual, physical, social, and emotional health. Nurturing all areas is important.

Ongoing Decision-Making Calls for Ongoing Support

As a healthcare provider, remember that, for a cancer survivor, the ordeal of cancer is never over. The crisis may be over, but most cancer survivors and their families have ongoing cancer-related concerns that call for regular cancer-related decision making.

The most common ongoing concern is the fear of cancer recurrence. Kathy's words in Scenario 7, for example, reveal the concern Kathy and her family have about the possibility of recurrence. Kathy made the decision not to concentrate on fear; instead, she channels her energy into activities she enjoys.

In addition to deciding how to deal with the fear of recurrence, a cancer survivor may face choices relating to medications, nutrition, sexuality, healthcare financing, work, education, children, fatigue, pain, neurologic problems, and altered body image.

Many cancer survivors say that the experience of cancer changes their lives forever. Some say the experience helps them to understand themselves, their faith, and their families better. Some say the experience changes their priorities, making them more appreciative of their families and friends and more aware of the fragility of life. (Scenario 6, Jeannine's story, showed how the cancer experience changed Jeannine's priorities.) Some survivors say they are two different people: the person they were before the diagnosis and the one they are now.

If you work with cancer survivors, you will have to provide long-term support for ongoing decision making. Be patient; keep in mind how many issues the patient may be dealing with. These issues include new physical limitations; fatigue; and uncertainty about how employers, coworkers, and friends will react after learning about the cancer diagnosis. Encourage the survivor to make decisions that support the creation of a new, desirable identity, not the re-creation of an old identity that cannot be recaptured. Share with your patients the guidelines in Figure 4-1, and review them frequently yourself to spark ideas about practical ways to help individuals and as a reminder about how to achieve a healthful balance in your own life.

References

Harpham, W.S. (1994). *After cancer: A guide to your new life.* New York: W.W. Norton.

Hinds, P.S., Oakes, L., Furman, W., Foppiano, P., Olson, M.S., Quargnenti, A., et al. (1997). Decision making by parents and healthcare professionals when considering continued care for pediatric patients with cancer. *Oncology Nursing Forum, 24,* 1523–1528.

Lewis, M.L., Corcoran-Perry, S.A., Narayan, S.M., & Lally, R.M. (1999). Women's approaches to decision making about mammography. *Cancer Nursing, 22,* 380–388.

Prochaska, J.O., Velicer, W.F., Rossi, J.S., Goldstein, M.G., Marcus, B.H., Rakowski, W., et al. (1994). Stages of change and decisional balance for 12 problem behaviors. *Health Psychology, 13*(1), 39–46.

Stanton, A.L., Estes, M.A., Estes, N.C., Cameron, C.L., Danoff-Burg, S., & Irving, L.M. (1998). Treatment decision making and adjustment to breast cancer: A longitudinal study. *Journal of Consulting and Clinical Psychology, 66,* 313–322.

Figure 4-1. Guidelines for Living After the Diagnosis of Cancer

After receiving a cancer diagnosis, patients make many decisions that are critical to long-term quality of life. Introduce your patients to the suggestions that follow. They will guide your patients during decision making and help them maintain the strength decision making requires.

- Secure as much information as you can about life after a diagnosis of cancer. Knowledge is power. Chapter 2 of this monograph lists many resources. Local librarians and healthcare professionals can provide many more.
- Set realistic goals and nourish inspiring dreams.
- Look to building a new you rather than re-creating the old you.
- Break up life challenges into manageable parts.
- Grieve your new losses.
- Realize that recovery after cancer is a family affair.
- Learn to control your reaction to bad thoughts or feelings.
- Laugh every day.
- Be aware that you cannot always choose your circumstances, but you can choose how you deal with them.
- Love yourself.
- Learn that coping with challenges gives you the strength to face them and the confidence that you can get through them.

Chapter 5:
Negotiation

Mary Gullatte, RN, MN, ANP, AOCN®, FAAMA

Chapter Goal

The goal of this chapter is to help oncology professionals to teach the negotiation process to patients, caregivers, and oncology professionals.

Introduction

Zartman and Rubin (2000) defined negotiation as joint decision making, under conditions of conflict and uncertainty, in which different viewpoints are combined to form a single outcome. Negotiation skills can help patients get the medical care they prefer, settle disagreements with insurers and providers, and protect their legal rights. Negotiation skills also are important for caregivers. A caregiver may have to represent the patient in communication with the healthcare team, insurers, and other parties. In addition, a caregiver may have to negotiate on his or her own behalf to get the respite care or support needed to continue meeting the patient's care needs.

Overviews of Negotiation

Fisher, Ury, and Patton's Model

Fisher, Ury, and Patton (1991) offered four points to consider before entering into negotiation.
- Separate the people from the problem; depersonalize the negotiation. Stick to the issue. Do not be distracted by the interplay of personalities.
- Focus on interests, not positions. Your interest is what you hope to maintain or gain. Your position is what you are for or against.
- Invent options for mutual gain; think through possible options that will work for both of you.
- Insist on using objective criteria. Do not let the criteria be emotion-based.

Gotbaum's Principles

Gotbaum (1999) identified four basic principles to keep in mind when preparing for negotiation.
- View yourself as a negotiator.
- Analyze your adversary's negotiating style and ability.
- Evaluate the stakes and the need for the negotiation.

- Understand the context of the negotiation.

In addition, Gotbaum noted that negotiating is a face-to-face human drama that can be as genteel as croquet or as brutal as a prizefight. Gotbaum hypothesized that the six attributes of successful negotiators are authority, power, principle, intellectual ability, knowledge of personal limitations, and sensitivity.

The Negotiation Process

Encourage patients and caregivers to enter every negotiation with a can-do attitude. Remind them that decisions about treatment planning are, ultimately, theirs. They are in charge and have the final say about the what, when, who, and how of their cancer treatment plan.

The remainder of this section will present five steps that relate to preparing for or participating in a negotiation. The list that follows presents other tips about negotiation.
- Communication skills, especially listening skills, are vital to successful negotiation.
- Some negotiators find that bringing a supportive person to the negotiation can be helpful. Make sure that person knows in advance what you want his or her role in the negotiation to be.
- Bringing a list of questions to the negotiation can be helpful.
- Notes taken during the session can be a valuable record of the event. If you are tense about the negotiation, note taking can be a useful means of hiding your anxiety. If taking notes distracts you, however, ask someone else to do it for you.

Step 1: Gather Information

When negotiating for anything, be as prepared as possible. Being prepared means gathering as much information about the negotiation as you can. Try to find the answers to the questions that follow.

- What do you know about the person with whom you are negotiating?
- What are his or her values?
- What does the other negotiator hope to gain?
- What are your needs and rights?
- What are you willing to accept?
- What do you ultimately want out of the negotiation (i.e., the desired end point)?

Stephen Covey (1989) put it another way: "Begin with the end in mind" (p. 97). In other words, decide what you want, define the obstacles that could prevent you from getting it, and determine ways to avoid or overcome the obstacles.

Step 2: Plan the Agenda

After gathering the information needed, make a written plan of action. The agenda of patients with cancer often involves learning. Encourage patients to make a list of all the things they want to learn and to prioritize the list according to the importance of the question to the patient. The first step to ensuring that the questions are answered is to schedule enough time for question answering. Remind patients to ask the receptionist or appointment secretary to schedule extra time if the list of questions is extensive.

Step 3: Set Limits

Setting limits involves clearly defining what you, as a negotiator, are willing to give up to get what you want. Gotbaum (1999) wrote that a key strategy in negotiation is to know yourself. Know what you want going into the negotiation and what you are willing to accept and reject as the consequences of that decision. Ask yourself, What is the point at which I am willing to walk away from the negotiation? Know what the next step will be if you do walk away.

Setting limits is a difficult skill to master. As a nurse, you can help patients develop the skill by suggesting that they practice negotiating in a role-playing situation. The person the patient practices with should be trustworthy and willing to give open and honest feedback.

Step 4: Be Aware of Your Inner Voice

The term *inner voice,* in the context of negotiation, is the message you receive from your own emotions. The inner voice can be a powerful force in negotiation. It can affect the terms you favor for acceptance or rejection, and it can have a strong effect on the tone in which you conduct your negotiation.

For example, suppose you had a bad experience with a specific insurance company. Now, as a caregiver, you find yourself negotiating with the same company on behalf of a patient. A frank critique of your own demands reveals that you are holding out for more than the patient asked for. Why? Your inner voice is urging you to punish the company for what you perceive as poor treatment in your own case. Similarly, you may enter the negotiation with combative attitude, using terms and a tone of voice tha reflect emotions left over from your own experience. Thos aggressive words are your inner voice talking. The emo tions it is expressing are irrelevant to the current negotia tion and will do it nothing but harm.

Teach patients and caregivers to be aware of the inne voice and how it is affecting them. Are they being stub born in negotiation because they feel personally slighte by the other negotiator, who was late and did not apolo gize? Does the inner voice whisper "give in" because th other negotiator seems more experienced?

Teach negotiators to keep their own voice separate from the inner voice. The key to doing this is to focus on the current issue and, as Fisher et al. (1991) pointed out, separate the people from the problem. Recognize, for example, that the other negotiator intimidates you. Recognize also that feeling intimidated need not affect what you will settle for. The two issues are unrelated.

Teach negotiators that physiologic states can alert them to the fact that they may be acting emotionally. These states are sweating, an increase in heart rate and respiration, an increase in the volume of the voice, and a change in the tone of the voice. When these symptoms occur, the negotiator should assess the cause of the change and how it is affecting the negotiation. In most cases, yielding to emotion means losing control. Loss of control in negotiation usually means defeat.

Step 5: Create a Win-Win Solution

Remember that the goal of the negotiation is to reach an agreement amicably and efficiently. This can mean compromising to show that you are reasonable and want to reach an agreement without wasting the other negotiator's time and resources.

If you can yield a point to the other party without compromising your goal, do it. This will give your counterpart a "trophy" to take away from the negotiation. By making a concession, you save the other negotiator from feeling defeated or, in the view of his or her organization, being defeated. If you yield on an unimportant point, your "adversary" may be more likely to yield on an important point.

The key to knowing how to create a win-win situation lies in step 1, gathering information, and step 3, setting limits. In step 1, discover what concessions the other negotiator is likely to prize. In step 3, survey your own motives and resources to discover the points you can afford to yield.

Negotiation Scenarios

The dialogs that follow deal with issues that typically concern people who are dealing with cancer. Each dialog relates to a specific step in the negotiation process. The patient (Bob) or a caregiver (Anita) states a problem. The reply shows how an oncology professional can help to resolve the problem.

Scenario 1: Information Gathering

Bob: I am afraid of sounding dumb if I ask the wrong question. I just do not feel comfortable asking questions.

Oncology professional: Bob, don't be afraid to speak up for yourself. There is no "dumb" question. Pretending that you understand or not asking questions will only make things worse. You have nothing to lose and everything to gain when you understand what is going on with your care. Throughout the course of your disease and treatment, at any time, ask your healthcare team to explain what you do not understand.

Bob: How can I get more information so I feel that I really understand my disease and the possible treatments?

Oncology professional: Make sure the information you gather is current and comes from a reliable source. Information from the American Cancer Society and the National Cancer Institute is reliable. I will give you some pamphlets, and you can also get information from the Internet. I will give you the addresses of some specific Web sites you can trust, including the Oncology Nursing Society's site, ONS Online.

Scenario 2: Agenda Planning

Bob: After I get all this information, how do I organize it so I won't get confused? There is so much information out there. What if I find a recommendation that is different from what my doctor or nurse is recommending?

Oncology professional: Bob, the first thing for you to do is limit your information gathering to a couple of credible sources. One way to organize your information is according to three categories: information about your disease, information about treatment, and survival data. Outline questions for the oncology team according to those three categories. In each category, put your most important question first. Be assertive in your communication with the oncology team, and ask the questions you need to clarify information.

Scenario 3: Setting Limits

Bob: What do I do if my insurance company refuses to give me what I want?

Oncology professional: Think about who you are, what you bring to the negotiation, and what you want. Write down your limits before beginning to negotiate. Plan what to do next if the negotiation fails. This could include involving other resources.

Scenario 4: Being Aware of the Inner Voice

Bob: I am so angry with my insurance company that I don't know if I can keep my cool.

Oncology professional: Try not to let your emotions get out of control during the negotiation. Think through your plan and what you want to gain as a result of the negotiation. It might help to write your goal. Try to analyze what triggered your negative emotions. Stop for a moment, sit back, take a deep breath, unfold your arms, and collect your thoughts. Focus on interests, not positions. Remember, if you lose control, you may lose the battle. Stay focused on the issue.

Scenario 5: Creating a Win-Win Solution

Anita: I have to run an errand on Friday, the day after Bob's chemo. The only person who can be with our son, Timmy, that day is Aunt Martha. I know coming over is an inconvenience for her, and I've already asked her to babysit twice this month. My stomach is in a knot about this. I wish I could ask someone else, but there just *isn't* anyone else.

Oncology professional: Can you think of something you can do for Martha that would make babysitting less inconvenient for her? Maybe you can do some of her errands while you're out. Or have her favorite video ready to start when she arrives. Your actions will tell her how much you appreciate her effort.

References

Covey, S.R. (1989). *Seven habits of highly effective people.* New York: Simon & Schuster.

Fisher, R., Ury, W., & Patton, B. (1991). *Getting to YES: Negotiating agreement without giving in* (2nd ed.). Boston: Houghton Mifflin.

Gotbaum, V. (1999). *Negotiating in the real world.* New York: Simon & Schuster.

Zartman, I.W., & Rubin, J. (2000). *Power and negotiation.* Ann Arbor: University of Michigan Press.

Chapter 6:
A Special Advocacy Challenge –
Being Effective in the Health Policy Arena

Elizabeth G. Gomez, RN, MSN

Chapter Goal

The goal of this chapter is to raise awareness of the ways in which healthcare professionals can influence health policy and inspire others to take action.

Introduction

In general, political advocacy is not a skill taught to students of healthcare disciplines. This chapter will present ideas that will help you to become more involved in political advocacy and support the efforts of patients who want or need to become political advocates. As a healthcare professional, you have an obligation to use your voice as issues that affect the delivery of quality health care arise. The opportunities to participate in the debate on health policy issues exist at the local, state, and national level.

Register to Vote

If you are a naturalized U.S. citizen, you have the right to vote. If you are eligible to vote and have not registered, do so now! It is easy, and you do not need to become affiliated with a major party to do so. You may complete a voter registration application in person at the election office in your county. Voter registration applications also are available at public libraries; at many institutions of higher learning; and at social services administrations, motor vehicle departments, offices on aging, and state departments of health.

In addition, you can use the Internet to submit a voter registration form by using the online form at www.election.com.

You are considered a registered voter when you receive your voter verification card from the local election board.

Understand the Legislative Process

Forgot your high school civics? How does a bill become a law? Take a moment to review Figure 6-1, which presents the 13 steps of the legislative process.

Understand Who the Players Are: Congressional Staff Roles

Each member of Congress has a staff to assist him or her during the member's term in office. To be most effective in communicating with Congress, it is helpful to know the titles and principal functions of key staff.

- **Administrative assistant or chief of staff.** The administrative assistant reports directly to the member of Congress. He or she usually has overall responsibility for evaluating the political outcome of various legislative proposals and constituent requests. The administrative assistant usually is the person in charge of office operations, including the assignment of work and the supervision of key staff.
- **Legislative director, senior legislative assistant, or legislative coordinator.** The legislative director usually is the staff person who monitors the legislative schedule and makes recommendations regarding the pros and cons of particular issues. In some congressional offices, several legislative assistants are assigned to staff, and each has expertise in specific areas. For example, depending on the responsibilities and interests of the member, an office may include a different legislative assistant for health issues, environmental matters, or taxes.
- **Press secretary or communications director.** The press secretary's responsibility is to build and maintain open and effective lines of communication between the member, his or her constituency, and the general public. The press secretary is expected to know the benefits, demands, and special requirements of both print and electronic media, and how to promote the member's views most effectively.
- **Appointment secretary, personal secretary, or scheduler.** The appointment secretary usually is responsible for allocating a member's time among the many demands that arise from congressional responsibilities, staff re-

Figure 6-1. The Legislative Process

Anyone may draft legislation; however, only members of Congress can introduce it and, by doing so, become the sponsors of the legislation. The four basic types of legislation are bills, joint resolutions, concurrent resolutions, and simple resolutions. Before any type of legislation enters the legislative process, it receives an identifying number. The prefix *H.R.* signifies that the legislation originated in the House of Representatives. The prefix *S.* signifies that the legislation originated in the Senate. The Government Printing Office prints the text of the legislation. Then the 13-step legislative process begins. Legislation may move from step 2 to step 5 without going to a subcommittee.

Step 1. Referral to committee
With few exceptions, legislation is referred to standing committees in the House or Senate, according to carefully delineated rules of procedure.

Step 2. Committee action
When legislation reaches a committee, discussion of it is scheduled, and the discussion date is noted on the committee's calendar. Legislation can be referred to a subcommittee or considered by the committee as a whole. It is at this point that legislation is examined carefully and its chances for passage are determined. If the committee does not act on legislation, it is the equivalent of killing it.

Step 3. Subcommittee review
Legislation often is referred to a subcommittee for study and hearings. Hearings provide the opportunity to put on the record the views of the executive branch, experts, other public officials, and supporters and opponents of the legislation. Testimony can be given in person or submitted as a written statement.

Step 4. Mark up
When the hearings are completed, the subcommittee may meet to mark up the legislation—that is, make changes and amendments prior to recommending it to the full committee. If a subcommittee votes not to report legislation to the full committee, the legislation dies.

Step 5. Committee action to report legislation
After receiving a subcommittee's report about legislation, the full committee can conduct further study and hearings or it can vote on the subcommittee's recommendations and any proposed amendments. The full committee then votes to decide what to recommend to the House or Senate. This procedure is called ordering legislation reported.

Step 6. Publication of a written report
After a committee votes to have legislation reported, the committee chair instructs staff to prepare a written report about the legislation. This report describes the intent and scope of the legislation, its impact on existing laws and programs, the position of the executive branch in regard to the legislation, and the views of dissenting members of the committee.

Step 7. Scheduling floor action
After the committee report is delivered to the chamber where the legislation originated, discussion of the legislation is scheduled. The House maintains several legislative calendars, and the speaker and majority leader are largely responsible for determining if, when, and in what order legislation is discussed. The Senate maintains only one legislative calendar.

Step 8. Debate
When legislation reaches the floor of the House or Senate, the legislation is discussed according to rules that determine the conditions of debate and the amount of time allocated to discussion.

Step 9. Voting
After debate and possible approval of amendments, the members pass or defeat the legislation by voting.

Step 10. Referral to the other chamber
When the House or Senate passes legislation, it is referred to the other chamber, where it follows a route through committee and floor action. The chamber to which the legislation is referred may approve the legislation as received, reject it, ignore it, or change it.

Step 11. Conference committee action
If the second chamber makes only minor changes to legislation, it is common for it to go back to the first chamber for concurrence. However, when the actions of the second chamber alter the legislation significantly, a conference committee is formed to reconcile the differences between the House and Senate versions. If the conferees are unable to reach agreement, the legislation dies. If they reach an agreement, the conference committee prepares a report that outlines the committee members' recommendations for change. Both the House and Senate must approve the conference report.

Step 12. Final actions
After the House and Senate have approved legislation in identical form, it is sent to the president. If the president signs it, it becomes law. The president has 10 days to sign or veto the legislation. If Congress is in session and the president has not signed the legislation within 10 days, it becomes law without his signature. If Congress is adjourned and he does not sign within 10 days, the legislation dies. Killing legislation by failing to act while Congress is adjourned is called a pocket veto.

Step 13. Overriding a veto
If the president vetoes legislation, Congress may attempt to override the veto. This requires a roll-call vote of the members, who must be present in a number sufficient to form a quorum. A two-thirds majority of the total members in each chamber is required to override a veto—that is, 290 positive votes in the House and 67 in the Senate.

quirements, and constituent requests. The appointment secretary also may be responsible for making travel arrangements and arranging speaking dates and visits to the district.

- **Caseworker.** The caseworker is the staff member usually assigned to help with constituent requests by preparing replies for the member's signature. The caseworker's responsibilities also may include helping to resolve constituents' problems with federal agencies (e.g., problems involving Social Security, Medicare, veterans' benefits, passports).

Inform Yourself

Subscribe to and read professional publications. They may be the first to alert you to trends in health care that require your attention. Read local newspapers to stay abreast of healthcare issues in your area, and read about national issues by following stories in the national media. In addition, be aware of the issues defined by and the information available from

- **Oncology Nursing Society (ONS), at www.ons.org.** ONS is a national organization of more than 30,000 registered nurses and other healthcare professionals dedicated to excellence in patient care, teaching, research, administration, and education in the field of oncology. The vision of ONS is to lead the transformation of cancer care. The society pursues this vision by initiating and actively supporting educational, legislative, and public awareness efforts to improve the care of people with cancer.
- **American Society of Clinical Oncology (ASCO), at www.asco.org.** ASCO has been one of the leaders in defining quality cancer care. As the healthcare industry continues to undergo rapid changes, ASCO has been concerned that cost-cutting measures may infringe on quality patient care. ASCO strongly believes in the right of all patients with cancer to receive the highest possible standard of medical care and has developed criteria to guide physicians, healthcare professionals, and public policy officials in ensuring quality cancer care.
- **The Center for Patient Advocacy, at www.patientadvocacy.org.** The center, founded in 1995, focuses on keeping the patient at the center of the healthcare debate. This organization focuses on the healthcare debate in Washington and access-to-care issues.
- **The National Coalition for Cancer Survivorship (NCCS), at www.canceradvocacy.org.** NCCS, the only patient-led advocacy organization working on behalf of people with all types of cancer and their families, is dedicated to ensuring quality cancer care for all Americans. A free NCCS publication, *What Cancer Survivors Need to Know About Health Insurance*, reviews types of health insurance, the basics of Medicare, what to do if a claim is denied, and legal protections for patients.
- **Thomas, at http://thomas.loc.gov.** Thomas makes federal legislative information available at no cost via the Internet. A service of the Library of Congress launched in 1995, it focuses on pending legislation and presenting the *Congressional Record* and committee information.

Inform Others and Voice Your Opinion

If you hear of legislation that affects the delivery of quality health care, you have the right and responsibility to make your opinion known to the public and your government representatives.

Send Letters to Local and Regional Media

If you find an issue particularly compelling or intriguing, chances are others will too. Write a brief letter to the editor of your local or regional paper, expressing your opinion about a healthcare issue. You have a better chance of being published in a small paper than in a large paper. In every case, your chance of being published is better if your letter relates in some way to a "hot" news story or a disease-awareness day or month.

Telephone Your Representatives

Finding Telephone Numbers

The Web sites that follow incorporate searchable databases that will allow you to find your representatives' telephone numbers.

- Thomas, at http://thomas.loc.gov
- The U.S. Senate Web site, at www.senate.gov
- The U.S. House of Representatives Web site, at www.house.gov

If you need to know what district you are in or the name of your representative and do not have Internet access, telephone the local library. The librarian will be able to give you that information as well as the address and telephone number of your representative. If you know your representative's name, find his or her telephone number by looking in the blue pages of the local telephone book in the U.S. Government section. Representatives' telephone numbers are listed under "Congress." Another way to telephone your representative is to call the U.S. Capitol switchboard, at 202-224-3121, and ask for the office of the representative who serves your district. If you do not know your district, the switchboard operator will determine it by asking you for your zip code.

Maximizing the Effect of Your Call

Remember that telephone calls usually are taken by a staff member, not the member of Congress. Ask to speak with the aide who handles the issue on which you wish to comment, in this case health or if you are addressing staffing issues, labor.

After identifying yourself, tell the aide you would like to leave a brief message, such as

"Please tell [Senator/Representative] [representative's name] that I [support/oppose] [S. [bill number]/H.R. [bill number]."

Also state the reasons for your support or opposition to the bill. Ask for your senator's or representative's position on the bill. You may request a written response to your call.

Send a Letter or E-mail to a Member of Congress

Which communication has more impact? An e-mail or a letter sent through U.S. mail?

According to one source (Current Alerts, 2002), some representatives ask staff members to report how many e-mails they receive in support of an issue and how many against an issue; they do not request counts relating to postal correspondence or any other means of communication. For these representatives, e-mail is probably the single most powerful means of learning the prevailing view of constituents. Certainly e-mail has the potential to be more immediate and interactive than a letter ("E-mail Still," 2001).

Another source ("Does Congress Have an E-mail Problem?," 2001) reported that other representatives view e-mails with skepticism because they tend to be written more hastily and carelessly than letters. Many members have soured on e-mail because so many senders abuse e-mail functions. They send multiple e-mails to the same member or direct the same e-mail to many members simultaneously. Because of this abuse, some members have shut down their public e-mail accounts and now insist that constituents e-mail through the member's Web site only. Features on members' sites screen out junk e-mail, lessening the load that the member's staff must process.

The best course may be to send an e-mail to state your opinion and support it briefly. Then, in a letter sent by U.S. mail, take the time to expand and polish your phrases. Keep the language economical, however; the most effective letters usually are no longer than one page. Any communication should be carefully prepared and use the proper forms of address. (The next section will present the forms of address.) A letter can be handwritten or typed. Whether you use U.S. mail or e-mail, keep a copy of your communication after you send it. You may want to refer to it if a member of the congressperson's staff requests additional information.

Maximizing the Effect of Your Communication

Unfortunately, many who send e-mails to members of Congress forget to include their own names and U.S. mail addresses. In most cases, this oversight will mean that the e-mail will be disregarded. A member's staff reads only those e-mails that are from constituents, and the sender's name and postal address are the means of verifying that the sender lives in the member's district. For the same reason, the sender's name and inside return address are important components of a letter to a member.

In composing an e-mail, use business-letter format. Include your U.S. mail address, the recipient's address, and a salutation, just as you would if you were typing a letter. Place your e-mail address under your name. Taking the time to be this formal will increase the credibility of your e-mail message.

In e-mails and letters, include a telephone number so that a staff member can call with questions if he or she wants to follow up.

To maximize the effectiveness of your communication, apply the tips that follow.

- State, in the first paragraph, your purpose for writing.
- If the communication pertains to a specific piece of legislation, identify it accordingly (e.g., House bill H.R. [bill number]/S. [bill number]).
- Be courteous, to the point, and include key information, using examples to support your position.
- Address only one issue in each letter. If possible, keep the letter to one page.

Addressing Your Letter and Including a Greeting

To address a letter to a U.S. senator, use this format:
> The Honorable [full name]
> U.S. Senate
> Washington, DC 20515

To address a letter to a member of the U.S. House of Representatives, use this format:
> The Honorable [full name]
> U.S. House of Representatives
> Washington, DC 20515

In the letter itself, use the salutation that reflects the addressee's position:
> Dear Senator:
> Dear Representative:

If you are writing to the chair of a committee or to the speaker of the house, however, use one of these salutations:
> Dear Mr. Chairman:
> Dear Madam Chairwoman:
> Dear Mr. Speaker:

Does Petitioning a Legislator Make a Difference?

In a Web chat ("Live Chat," 2002), Ilisa M. Halpern, MPP—director of government relations at a Washington law firm—emphasized the need for and significance of public involvement in healthcare issues.

Many of you may wonder whether or not it makes a difference if you write, call, fax, e-mail, or meet with your elected officials or their staff—

and I can tell you from firsthand experience that it does! When I first arrived in Washington nine years ago, I worked for U.S. Senator Dianne Feinstein. . . . Every day before the senator would depart, she would ask for a report on the phone calls. She wanted to know how many people called in, what topics they discussed, and what side of the issue they were on. Once a week, she got a similar report on all the mail—letters, faxes, e-mail, etc. She took this constituent input into consideration, and it helped her to determine her position on issues. . . .

Your policymakers need and expect to hear from people in the real world—from you all who are on the front lines of the war against cancer. I call this the need for "legitimate voices" in the policymaking process.

Be a "legitimate voice." Be informed. Inform others. Voice your opinion, and help your patients voice their opinions and needs by being their advocates and teaching them advocacy skills.

References

Current alerts. (n.d.). Retrieved March 7, 2002, from http://legislation.cwfa.org/alerts/effectiveness.shtml

Does Congress have an e-mail problem? (2001, May 4). Retrieved March 7, 2002, from http://www.infoworld.com/articles/hn/xml/01/05/04/010504hncongress.xml?sponsor = BUSINESSNEWS

E-mail still an effective method for communicating to Congress. (2001, March 21). Retrieved March 7, 2002, from http://capitoladvantage.com/h/news/pr010321.html

Live chat transcript: Nursing shortage and Medicare reimbursement—Update and advocacy action (2002, January 10). Retrieved March 7, 2002, from http://www.cancersourcern.com/community archive.cfm?contentid = 24313

Appendix A: Glossary of Insurance and Healthcare Industry Terms

access. The availability of healthcare services. Factors n determining ease of access include the location of healthcare facilities and the hours of operation at the facilities.

accreditation. In regard to a healthcare organization, a rigorous on-site review, according to comprehensive standards, by a recognized independent agency.

actuarial. Relating to costs and utilization typical of a defined population. Actuarial data help to define health plan premiums.

actuary. An individual who helps to establish insurance policy rates by performing statistical calculations and analysis.

adjudication. Settling a claim in accordance with the terms of agreement between a provider and a health plan.

admission certification. Verifying that patients need to be admitted to a hospital. The admission certification process occurs either before or during admission.

alternative delivery systems. Any type of healthcare delivery except fee-for-service health care. Health maintenance organizations, preferred provider organizations, and most managed care organizations are alternative delivery systems.

approved charge. The amount a carrier will pay for a covered service.

assignment. Transference of responsibility for payment. A patient asks a provider to accept assignment from the patient to an insurer (e.g., Medicare) for payment in full.

assignment of benefits. A request that benefits resulting from a healthcare claim be paid directly to the provider of service.

average length of stay. The average number of days a patient remains in a hospital.

average wholesale price (AWP). The average price that pharmacies pay for a given drug. AWP does not include the costs of packaging medications for the consumer or distributing medications.

base capitation. An established dollar amount that reflects the cost of basic healthcare services for an individual.

beneficiary. The person eligible to receive insurance benefits under a specific policy.

cap. *See* capitation.

capitation. The payment per capita for a defined package of services. A specific amount per member is paid to providers or organizations of providers regardless of the quantity of services provided. Also called cap.

case management. Assigning a nurse or another healthcare professional to specific cases so the cases can be intensively monitored. The goals of case management are efficient coordination of care and proactive service that improves outcomes and uses resources efficiently.

case manager. A healthcare professional who coordinates a patient's care by working closely with the patient, providers, and insurers to ensure that the patient receives optimal, cost-effective healthcare services.

catastrophic case. A serious illness or accident that is complex, usually is life threatening, and consumes significant healthcare resources.

certificate of coverage. A document, required by state law, that lists health plan benefits for subscribers.

claims review. Assessment of a claim before payment is made.

closed panel. A group of healthcare providers or facilities that serves only the members of a health maintenance organization.

coinsurance. The portion of the cost of a healthcare service that an individual policyholder is required to pay.

commercial. Nongovernment. Medicare and Medicaid are government programs. Commercial programs include group and individual members.

concurrent review. A utilization review conducted during the course of actual treatment, usually for the purpose of monitoring the length and level of treatment provided. The term is used most frequently to describe inpatient reviews after admission.

contract. An agreement between a health plan and provider or a health plan and subscriber. A contract details benefits, copayments, limitations, exclusions, and the date on which coverage becomes effective.

copayment. A payment an individual policyholder or someone covered by a policy makes at the time he or she receives healthcare services.

cost-sharing provision. A provision in a health insurance plan that requires the insured to pay some portion of his or her covered health expenses. A cost-sharing provision could require the insured to pay coinsurance, copayments, and deductibles.

covered benefit. A medical service that a health plan's Evidence of Coverage document specifies as being medically necessary and covered under the terms of the contract between the plan and the subscriber.

credentialing. A provider review, according to specific criteria, to determine if the provider meets the requirements to begin participating in or remain a participant in a health plan. Credentialing helps to maintain quality standards in provider membership and potentially provides legal safeguards.

discounted fee for service. A rate, lower than the provider's customary fee, to which the provider and health plan agree.

drug formulary. A list of the prescription medications that a health plan approves for use, for which the plan will cover costs, and that participating pharmacies will dispense to plan participants.

electronic claims submission. Transmitting providers' claims for payment via an electronic medium (e.g., tape, diskette, modem) instead of by means of paper claim forms.

eligibility. Worthiness, according to preset criteria, of being covered by a plan at the time provider services are to be rendered.

enrollment area. The geographic area in which an individual must live to be eligible for health plan coverage.

exclusive provider organization (EPO). An organization that is like a preferred provider organization except that an EPO requires insureds to receive covered healthcare services from participating providers. The primary difference between an EPO and a health maintenance organization (HMO) is that an EPO is regulated by insurance laws and regulations or the Employee Retirement Income Security Act of 1974, which governs self-insured health plans, and an HMO is regulated by laws specific to HMOs.

exclusivity clause. A section, in a provider's contract with a health plan, stating that the provider cannot contract with more than one managed care organization.

fee for service. An arrangement under which doctors or other healthcare providers are paid separately for each service they perform.

gag clause. A provision in a provider's contract with a managed care organization that prevents the provider from discussing all available treatment options and financial incentives with patients. Also called gag rule.

gatekeeper. A primary care provider who coordinates all diagnostic testing and specialty referrals regarding a patient's medical care.

grievance procedure. The process a health plan stipulates for resolving health plan or provider complaints.

group contract. A health insurance contract, between an employer or organization and a health plan, that specifies the terms under which the employer or organization purchases health care for groups of individuals.

group insurance. Insurance purchased on behalf of individuals by an employer or large group.

group-practice model. A health maintenance organization model in which the organization contracts with one or more medical groups on a capitation basis for provision of services. The physicians practice in a common facility and use a common staff. Income is pooled and distributed according to an agreed-upon plan.

health maintenance organization (HMO). A company that provides health care to people who participate by choice, in a specific geographic area, according to a specific agreement about benefits.

Health Plan Employer Data and Information Set. A standard protocol that health plans and providers use to report specified data.

hold-harmless clause. A clause in most managed care contracts between a provider and a health plan. In the clause, each party agrees not to hold the other responsible in the event of malpractice or financial insolvency.

identification card. A card issued by a health plan to a plan member. The card presents membership information and certifies that the member cited is enrolled in the plan.

in network. Having a rate agreement with an insurance provider—in other words, being on the roster of a plan's providers. In-network providers can benefit from the agreement by receiving more patients and referrals.

indemnity health plan. A fee-for-service plan. The member pays a predetermined percentage of the cost of healthcare services and the insurance company pays the rest. Indemnity health plans allow members to choose their own healthcare provider.

managed care. A type of healthcare delivery that emphasizes active coordination of health services. Managed care usually involves three key components: the authority to oversee medical care, contractual relationships with and organization of the providers giving care, and benefits coverage that is regulated by health plan stipulations.

managed care health plan. A health plan that provides a managed care delivery system.

managed care organization (MCO). An insurance organization that provides benefits through a managed care model. Sometimes the term is used more broadly to include provider organizations that enter into managed care subcontracts with insurance organizations. The most common types of MCOs are health maintenance organizations and preferred provider organizations.

Medicare. Government health insurance program for Americans ages 65 and over and for some disabled people.

Medicare (Part A). The federal hospital insurance program that covers the cost of hospital and related posthospital services for those over age 65 or with certain disabilities. Eligibility usually is based on prior payment of payroll taxes. Beneficiaries are responsible for an initial deductible per episode of illness and copayments for some services.

Medicare (Part B). The supplementary federal medical insurance program for those over age 65 or with certain disabilities that covers the costs of physician services, outpatient laboratory tests and x-rays, durable medical equipment, outpatient hospital care, and certain other services. Part B requires payment of a monthly premium, and beneficiaries are responsible for a deductible and copayment for most covered services.

Medicare risk account. An arrangement between Medicare and a health plan under which the plan receives monthly capitated payments to provide Medicare-covered services for enrollees and thereby assumes insurance risk for enrollees. A plan is eligible for a risk contract if it is a federally qualified health maintenance organization or competitive medical plan.

Medigap. Private insurance that pays costs that exceed amounts that Medicare will pay. Also known as MedSupp.

open access. The characteristic of an HMO that allows HMO members to self-refer for specialty care (i.e., members can receive care from a participating provider without a referral from another doctor and without financial penalty).

open-ended HMO. A health maintenance organization (HMO) that allows its members to seek medical services outside its contracted provider panel.

open enrollment. The time during which people can select to enroll in a health plan or change their plan.

out of area. Not within the service area defined by a health maintenance organization.

out-of-pocket cap. An annual limit on how much, in deductibles and copayments, an insured person must pay. Also called out-of-pocket maximum or stop-loss provision.

partial hospitalization. A program that continues providing outpatient services after a patient has been discharged. Many hospitals offer chemical dependency and mental health programs on a partial-hospitalization basis.

participating provider. A provider who has contracted with a health plan to provide medical services to people the health plan covers.

physician-hospital organization (PHO). An organization through which physicians and hospitals jointly operate specific programs.

plan of benefits. The benefits, exclusions, limitations, maximums, copayments, coinsurance, deductibles, and conditions that define a specific policy.

point-of-service plan. A health plan whose members can choose to receive care from plan-specified providers or, at the same cost, from providers outside the plan.

portability. A provision of U.S. law that enables employees to change jobs without risk of losing insurance coverage. Portability is guaranteed for employees who meet specifications detailed in the Health Insurance Portability and Accountability Act of 1996.

preadmission certification. The process through which a health plan determines if inpatient care is necessary. Preadmission certification occurs prior to admission.

preexisting condition. An illness or condition that an individual has before he or she is covered by an insurance plan or while covered by a different plan.

preferred provider. A provider under contract with a health plan to provide services. Providers include physicians, pharmacies, or hospitals.

preferred-provider organization (PPO). A managed care plan that contracts with a network of providers to provide care. The contract specifies a discounted fee-for-service payment system. Enrollees receive financial incentives to use the services of the network providers.

primary care. Basic or general care as opposed to specialist or subspecialist care.

primary care provider. A healthcare professional responsible for monitoring a patient's overall healthcare needs and who can refer the patient to a specialist if necessary.

prior authorization. A health maintenance organization's permission for a patient to receive a specific service. Authorization usually must occur before the service is rendered.

traditional care. A model of health care in which patients choose whatever provider they wish; physicians order whatever services they feel are necessary; and the insurance provider is primarily passive, paying for all the services a physician orders, at the provider's usual rates.

wellness program. A program offered by a managed care organization to promote preventive medicine and a healthful lifestyle. Typical wellness programs deal with smoking cessation, nutrition, weight control, stress management, and fitness.

Appendix B: Acronyms

ACSW. Academy of Certified Social Workers

ADA. Americans with Disabilities Act

AHA. American Hospital Association

AMA. American Medical Association

CHAMPUS. Civilian Health and Medical Program of the Uniformed Services

COBRA. Consolidated Omnibus Budget Reconciliation Act

CON. certificate of need

CPT®. current procedural terminology (for physicians) (American Medical Association, Chicago, IL)

CQI. continuous quality improvement

DME. durable medical equipment

DOB. date of birth

DOS. date of service

DRG. diagnosis-related group

DSM-IV. *Diagnostic and Statistical Manual of Mental Disorders*, 4th edition, published by the American Psychiatric Association, Washington DC

DX. diagnosis

EAP. employee assistance program

EOB. explanation of benefits

HCFA. Health Care Financing Administration

HIPAA. Health Insurance Portability & Accountability Act

HMO. health maintenance organization

HSA. health service agreement

ICD. International Classification of Diseases; a system of coding and classifying mortality data taken from death certificates

ICD-9-CM. *International Classification of Diseases, 9th Revision, Clinical Modification*; a system of coding and classifying morbidity data from inpatient and outpatient records, physician offices, and most NCHS surveys

JCAHO. Joint Commission on Accreditation of Healthcare Organizations

LOS. length of stay

MAC. maximum allowable cost

MCO. managed care organization

MSO. management service organization

OSHA. Occupational Safety and Health Administration

PCN. primary care network

PCP. primary care physician

POS. point of service

PPO. preferred provider organization

PRO. professional [or peer] review organization

QA. quality assurance

QM. quality management

R&C. reasonable and customary

RFP. request for proposal

SNF. skilled nursing facility

U&C. usual and customary

UM. utilization management

UR. utilization review

YTD. year to date

Appendix C: Oncology Nursing Society
Position on Quality Cancer Care

Editor's note: This position statement was approved by the ONS Board of Directors in April 1997 and revised in July 2000.

Summary

The cost-reduction emphasis in healthcare restructuring threatens the delivery of quality cancer care. A primary focus on cost by payors and delivery systems signals an onerous intention to limit access to essential components of cancer care. This is exemplified in recent trends including:

- Payors restrict access to specialty oncology care;
- Payors impose limitations on selection of treatment options and access to supportive care services;
- Registered nurses are encouraged to generalize rather than specialize in oncology;
- Experienced oncology registered nurses, including expert advanced practice nurses and senior nurse executives, have lost jobs;
- Specialized oncology units have dissolved or combined with non-specialty units;
- Chemotherapy drugs are administered either by nurses lacking oncology knowledge and chemotherapy competencies or by lesser-skilled assistive personnel.

The oncology registered nurse role in the multidisciplinary team is pivotal in creating an environment conducive to quality patient care. **Therefore, it is the position of the Oncology Nursing Society that:**

- Quality cancer care is a right of all citizens;
- Quality cancer care entails timely access to and reimbursement for a coordinated, comprehensive approach to care provided by a multidisciplinary team throughout the cancer trajectory that includes prevention; early detection; treatment, including clinical trials; supportive care; long-term follow-up; and end-of-life care;
- Quality cancer care is culturally competent, ethical, and cost-effective;
- Quality cancer care incorporates the individual with cancer (and the family) as fully informed partners and decision-makers;
- Quality cancer care is coordinated and delivered by competent cancer care providers;
- Accountability and coordination of quality cancer care is best accomplished by registered nurses who have been educated and certified in the oncology specialty;
- Oncology advanced practice nurses should be utilized in all cancer care delivery systems;
- Oncology nursing must be included, with equal parity to that of medicine and other disciplines, in the planning and implementation of cancer care services.

Position

The cost-reduction emphasis in healthcare restructuring threatens the delivery of quality cancer care. The Oncology Nursing Society (ONS) asserts that any restructuring of healthcare systems must ensure effective, comprehensive, and safe cancer services. These services must be coordinated and delivered by competent cancer care providers. ONS further believes that all health plans must provide consumers access to and coverage of preventive and early-detection cancer services, with timely access to a coordinated team of multidisciplinary oncology specialists when cancer is suspected or diagnosed. Access to the team of oncology specialists must be provided throughout the cancer continuum, including definitive diagnosis and staging; treatment, including clinical trials; long-term follow-up; rehabilitation; and end-of-life care. Quality cancer care requires that the physical, psychosocial, and spiritual needs of individuals with cancer and their families be addressed. Cancer care should be provided in a cost-effective, ethical, and culturally competent manner. It must encourage active decision making by and participation of individuals with cancer and their families in the plan of care.

ONS affirms that the overall accountability and coordination of nursing care for individuals with cancer is best accomplished by registered nurses who have been educated and certified in the specialty of oncology. Oncology registered nurse services are essential and central to the provision of quality care at all phases of the cancer experience. Similarly, oncology advanced practice nurses, including clinical nurse specialists and nurse practitioners, should be used in all cancer care delivery systems to ensure cost-effective, expert care. In addition, ONS affirms the substantive role of nursing in decision making and full participation in the administrative structure of healthcare delivery systems. Oncology nursing must be included with equal parity to that of medicine and other disciplines when planning and implementing any restructuring of cancer services.

ONS further believes that quality cancer care is a right of all citizens, including the indigent, uninsured, underinsured, and those who, because of racial, cultural, economic, or geographic factors, find barriers to entering or staying in the healthcare system. ONS's position is that these access issues are not addressed effectively in the current restructuring activities.

Committed to removing barriers to the provision of quality cancer care, ONS has joined with other professional societies, patient-advocacy groups, and other organizations that hold similar values to ensure that the needs of individuals with cancer, rather than decisions based solely on cost, drive the provision of care. Strategic initiatives by ONS to achieve this goal include education of health professionals, patients, payors, the media, and the public; research on optimal cancer outcomes; and action to initiate and promote regulatory and legislative changes at the state and federal levels.

Background and Discussion

A primary focus on cost by payors and delivery systems signals an onerous intention to limit access to essential components of cancer care. ONS members report alarming trends that hamper the oncology registered nurse's ability to provide safe and necessary care. These trends include

1. Redirecting oncology registered nurses to focus on the delivery of medical-surgical generalist care, thus diminishing the ability of nurses to provide expert, specialized oncology care.
2. Terminating the employment of experienced oncology registered nurses, expert oncology clinical nurse specialists, and senior oncology nurse leaders and administrators.
3. Dissolving specialized oncology units and "de-skilling" nursing care so that nurse-to-patient ratios are significantly decreased. Increasingly, direct care is being provided by less-costly, less-skilled assistive personnel.
4. Permitting cancer chemotherapy to be administered by nurses who do not have oncology knowledge and have not demonstrated chemotherapy administration competence. In some cases, assistive personnel are permitted to administer chemotherapy.

Consumers report that they are unable to determine the professional status of those providing their cancer care. Some healthcare facilities reinforce this assumption by removing credentials from name tags, including RN identification and the designation of oncology certification, thus reinforcing the assumption that everyone is equally qualified and skilled in providing cancer care.

Other trends that demonstrate the intention to limit access to necessary cancer care include health plans that are unwilling to provide coverage for the cost of patient care associated with cancer clinical trials. This is a major concern as clinical trials are the primary method for advancing knowledge in cancer prevention, detection, and treatment. Some payors limit patient choice among standard cancer treatment approaches. Necessary symptom management and supportive care are being limited. For example, certain health plans restrict formularies so that more expensive, yet essential, first-line drugs for symptom management, such as those for nausea and vomiting, are restricted. Some health plans may limit access to oncology specialists. The complexity of cancer care and follow-up monitoring and the continuing need to find curative treatment strategies, better symptom management, and improved palliative care require cancer care delivered by healthcare providers with specialty preparation. Finally, restructuring of care is accelerating the shift in cancer care from hospital and clinic to the home and family, yet the provision of homecare services by oncology nurses has been reduced or is severely limited. The family's out-of-pocket expenses and caregiver burdens have not been addressed. Families are asked to be the primary caregivers in the home but have insufficient support, knowledge, and resources to render the complex care asked of them.

Definitions

ONS subscribes to the Institute of Medicine's definition of quality of care that states, "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." ONS defines the cancer continuum to include prevention, early detection and accurate diagnosis, treatment, symptom management, education and supportive care that includes family members, rehabilitation, long-term follow-up for survivors, and palliative care for those at the end of life. ONS recognizes that incorporating the following elements in a comprehensive, coordinated, multidisciplinary approach constitutes quality cancer care.

Prevention entails activities that educate the public about cancer risks and lifestyle changes that can decrease the incidence of cancer in a manner that is effective for diverse populations. These activities should include services such as smoking cessation and prevention programs, nutritional counseling, fitness programs, cancer risk assessment, and counseling and education about the prevention of environmental exposures. As effective chemopreventive therapies are found, ONS believes they should be covered by health plans.

Early detection entails reimbursement for screening activities that facilitate the early detection of malignancies when they are most curable. Evidence-based guidelines should be used for cancer screening and implementation through programs that address the needs of diverse populations. Routine comprehensive screening should be available to all citizens and, based on screening guidelines, tailored to individual risk, including family history, age, sex, and race. Regular, complete screening should include such services as comprehensive physical examination, risk assessment and education, mammography, Pap tests, digital rectal exam, prostatic specific antigen levels, sigmoidoscopy/colonoscopy, skin assessment, and, when appropriate, cancer genetic risk testing that includes comprehensive counseling and informed consent.

Treatment entails timely access to the range of treatment modalities best suited for management of the specific cancer. These include surgery, radiation therapies, chemotherapy, hormonal therapies, biological therapies, bone marrow or peripheral blood progenitor cell transplant, complementary therapies, and rehabilitation therapies. Chemotherapy must be administered only by registered nurses who successfully complete ongoing institutional-based competency validation programs that are consistent with ONS's guidelines for chemotherapy administration. Individuals with cancer must have access to participation in scientifically sound clinical trials, and informed consent must be a component of trial participation. Information gleaned from trial data is necessary to advance the implementation of effective screening, diagnostic, and treatment modalities and to establish new practice guidelines, clinical pathways, and standards of care.

Supportive care entails the provision of comprehensive symptom management; education for individuals with cancer and their families about cancer treatment, toxicities, and side effect management; and timely access to competent community resources for care in the home. Symptom management includes both control of physical symptoms, such as fatigue, pain, and nausea, and psychosocial care, such as support groups and individual and family counseling. Comprehensive supportive care is essential to enhancing the quality of life of individuals with cancer and their families.

Long-term follow-up entails ongoing access to rehabilitative services and follow-up by oncology specialists for survivors of cancer. Services should include specialized clinics that focus on health promotion, subsequent disease prevention, prompt detection of recurrence, and the timely identification and treatment of both physiologic and psychosocial sequelae of cancer and cancer treatment.

End-of-life care entails access to palliative care modalities that improve quality at the end of life. The current societal focus on assisted suicide reinforces the need for the healthcare system to ensure appropriate care for individuals at the end of life. Quality care incorporates services such as patient and family participation in decision making, competent and comprehensive symptom management, attentive psychosocial support for patients and their families, hospice care, and bereavement counseling. End-of-life care must be provided in a culturally competent manner with respect to inherent spiritual and ethical issues.

Conclusion

ONS is committed to vigorously promoting quality of life for those experiencing cancer through services coordinated and provided by competent oncology registered nurses throughout the continuum of care and in all settings. ONS recognizes the need for ensuring cost-effective approaches to care that maintain quality. Quality cancer care, as defined in this position, has a direct impact on cancer outcomes and is essential to the well-being of those experiencing cancer. ONS believes that there is a moral obligation to make decisions guided by quality, rather than by cost alone, in all healthcare restructuring efforts.

Appendix D: American Society of Clinical Oncology
Statement on Access to Quality Cancer Care

Background

With rapid changes in the health care industry, there is concern among patients and oncology professionals that cost-cutting measures may result in substandard care for the 1.2 million Americans in whom cancer is diagnosed each year. Amid such change, it is critical that all people with cancer receive the best possible treatment to maximize the likelihood of survival and to enhance quality of life.

The American Society of Clinical Oncology (ASCO) strongly affirms the right of patients, including those in managed care programs, to have access to a multidisciplinary team of cancer specialists across the entire continuum of care—prevention and early detection, state-of-the-art treatment after diagnosis, and hospice and palliative care for terminal illness.

In April of 1999, the Institute of Medicine National Cancer Policy Board (NCPB) issued a report that suggested many people with cancer are not receiving care known to be effective for their disease. The NCPB believes the problem is significant, but there are insufficient data to determine the true extent and nature of the problem. There is currently no national monitoring system that provides meaningful information about treatment and quality of care for patients with cancer in the United States.

Key questions
- What defines quality cancer care?
- How can high-quality care be ensured?
- How can we improve what we know about the quality of cancer care?

National Initiative on Cancer Care Quality (NICCQ)

In response to the NCPB report, ASCO has launched a groundbreaking study, the National Initiative on Cancer Care Quality, that will design and test the kind of information system needed to determine how cancer care is provided to patients across the United States. The goal: to identify and disseminate information about practices associated with the best outcomes through timely reporting on all aspects of care—from screening and diagnosis to end-of-life care; and to provide consumers information they may use to make appropriate choices in obtaining cancer care services.

Major elements of the NICCQ
- ASCO is partnering with research teams from RAND and Harvard University who are experts in a broad range of health care quality and outcomes.
- Using the American College of Surgeons' National Cancer DataBase, researchers will identify a sample of adult patients who have been diagnosed with breast or colon cancer, two of the most common forms of cancer for men and women. Areas of examination include demographics such as health insurance, patient characteristics, location, health care system structure and types of providers.
- Five major professional oncology societies will collaborate with ASCO: the American College of Surgeons, the Society of Surgical Oncology, the American Society of Therapeutic Radiology and Oncology, the Society of Gynecologic Oncologists, and the Oncology Nursing Society.
- The Susan G. Komen Breast Cancer Foundation, which has contributed $1 million, is a major supporter of the study. Other sponsors include Bristol-Myers Squibb, Aventis Oncology, Amgen, Inc., Agouron Pharmaceuticals, Inc., Ortho Biotech, Immunex Corporation, and the National Pharmaceutical Council.
- The research teams have selected Houston, Los Angeles, and Cleveland as the three U.S. metropolitan areas to be studied. Additional cities are under consideration and may be added.
- A broader follow-on study will be used to determine the extent of variations in practice across a variety of cancer treatment settings, medical circumstances, and patient demographics.

Elements of Quality Cancer Care

ASCO is a signatory to a joint 1998 statement by the American Federation of Clinical Oncologic Societies—a coalition representing more than 50,000 cancer healthcare professionals—which defines the key terms of quality cancer care, including the following:

Diagnosis
Timely access to cancer screenings and other diagnostic tests
Minimal delay between time of diagnosis and time of treatment
Accurate determination of the extent of disease (staging) at the time of diagnosis and relapse

Treatment
- Coverage of all medically appropriate, state-of-the-art cancer treatment
- Coverage of routine patient-care costs associated with participation in clinical trials, which can represent the best hope for effective cancer treatment for many patients
- Appropriate coverage for palliative and end-of-life care
- Direct and immediate access to appropriate cancer specialists, whether or not they belong to the patient's physician network
- Access to an oncologist as the primary care physician for patients participating in a managed care program
- Access to psychosocial care, including support groups, counseling, and medical interventions
- Ready access to pediatric oncologists for children, recognizing that childhood cancers are biologically distinct
- Access to long-term follow-up care and coverage of comprehensive rehabilitation services
- Participation in decision-making and full informed consent to treatment

Advocacy in Health Care:
Teaching Patients, Caregivers, and Professionals
Continuing-Education Post-Test

The Oncology Nursing Society is accredited as a provider of continuing education in nursing by the American Nurses Credentialing Center's Commission on Accreditation and by the California Board of Registered Nursing, Provider #2850.

Credit Hours: 3.3
Passing Score: 80%
Test ID # 02-593-01   Expiration Date: 11-30-04
Test Processing Fee: $15

1. Mrs. S. sits with the social worker while her husband is receiving his chemotherapy. She discusses that she feels like her husband is pulling away from her. She confides that they hardly talk at home anymore. He wants to "watch T.V." She begins to cry. Which of the communication skills would be the most appropriate for Mrs. S. to utilize when she addresses Mr. S.'s isolation?
   a. Assertiveness
   b. Active listening
   c. Expression of feelings
   d. Matching words with nonverbal communication

2. Mr. M., a caregiver for his wife, observes the doctor while his wife is talking to him. Which of the following would best describe active listening skills?
   a. Sitting across from the patient, paging through the chart, reading it.
   b. Standing at the doorway, turning around periodically when hearing others in the hall.
   c. Sitting across from patient, nodding to the nurse after several interruptions saying that he must leave temporarily.
   d. Sitting across from the patient, nodding his head appropriately and maintaining eye contact.

3. Martha is upset with her brother, John, who is refusing to see any of his classmates or friends since he started his chemotherapy. After Martha screamed at John that "He should see his friends!", John went to his room and shut the door. Which of the following would be the best form of communication for Martha to use?
   a. Assertiveness
   b. Active listening
   c. Use of "I" messages
   d. Matching words with nonverbal cues

4. Barriers to effective communication include
   a. Inappropriate nonverbal communication and second-guessing.
   b. Matching of nonverbal communication and active listening.
   c. Expressing feelings and using "I" messages.
   d. Expressing feelings and assertive communication.

5. Mr. B. has been discussing his concerns about his treatment with the oncology nurse. The nurse says, "What I hear you saying is that you are concerned about how much time you will be off from work." This statement is most reflective of which communication skill?
   a. Using "I" messages
   b. Expressing feelings
   c. Assertiveness
   d. Active listening

. When teaching negotiation skills to the patient and caregiver, the oncology health professional should instruct the patient to begin with which of the following action steps?
   a. Set limits.
   b. Plan an agenda.
   c. Gather information.
   d. Create a win-win solution.

7. Mr. T, a cancer survivor, asks the oncology social worker for information about a clinical trial to treat his recurrent cancer. Which of the following actions would be the most appropriate?
   a. Refer the patient to a comprehensive cancer center for study.
   b. Refer the patient to the oncologist or nurse practitioner.
   c. Tell the patient he is probably not eligible for a trial since his cancer has recurred.
   d. Suggest that the patient go to the local library and search the Internet.

8. Mr. Z. told his oncology nurse that his insurance company has denied coverage for his planned cancer treatment. The oncology professional talks with Mr. Z. about meeting with the insurance company to negotiate payment for the treatment. What is the correct sequence of action steps in the negotiation process?
   a. Gather information, plan the agenda, set limits, be aware of the inner voice, and create a win-win solution.
   b. Create a win-win solution, plan the agenda, control emotions, communicate, and set limits.
   c. Plan the agenda, control emotions, ask questions, gather information, and begin with the end in mind.
   d. Set limits, gather information, plan the agenda, communicate, and be aware of the inner voice.

9. Fisher and Patton have identified which of the following points to consider prior to beginning the negotiation process?
   a. Separate the person from the problem, focus on positions, invent options for mutual gain, and use subjective criteria.
   b. Separate the person from the problem, focus on interests, create a win-lose situation, and use objective criteria.
   c. Depersonalize the negotiation, focus on interests, invent options for mutual gain, and use objective criteria.
   d. Personalize the negotiation, focus on positions, create a win-lose situation, and use objective criteria.

10. Mrs. F. is feeling frustrated and angry with her healthcare insurer about her coverage for her cancer treatment. She realizes that she must negotiate with her insurer for payment. Which of the following would initially benefit Mrs. F. in preparing to negotiate?
    a. Write a plan of what she expects to gain, focus on the issues, and be aware of her inner voice.
    b. Focus on the issues, follow her instincts, and contact her lawyer for advice before going to the meeting.
    c. Gather the facts, contact her lawyer for advice, and take a friend with her to the meeting.
    d. Practice what she is going to say, be aware of her inner voice, and follow her instincts.
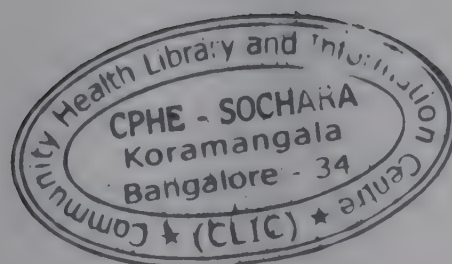
Advocacy in Health Care:
Teaching Patients, Caregivers, and Professionals

Post-Test Answer Sheet

Complete this form and the evaluation form on page 53 and submit them to:
Oncology Nursing Society
ATTN: ECCIT
Box 3510
Pittsburgh, PA 15230-3510

To receive continuing education (CE) credit for this monograph, simply:

1. READ all of the chapters in this monograph in their entirety.

2. Take the test and record your answers on the form below. Also complete the program evaluation form on page 53. (You may make copies of the answer form and evaluation.)

3. Mail the completed answer form along with a check or money order for $15 payable to the ONCOLOGY NURS-ING SOCIETY. Payment must be included for your examination to be processed.

4. The deadline for submitting the answer form is November 30, 2004.

5. Nursing contact hours will be awarded to participants who successfully complete the program. Successful completion is defined as an 80% correct score on the examination and a completed program evaluation. Verification of your CE credit will be sent to you. Certificates will be mailed within six weeks following receipt of your Post-Test/Evaluation Form. For more information, call 412-859-6249.

Instructions: Circle one answer.

1.	A	B	C	D		6.	A	B	C	D
2.	A	B	C	D		7.	A	B	C	D
3.	A	B	C	D		8	A	B	C	D
4.	A	B	C	D		9.	A	B	C	D
5.	A	B	C	D		10.	A	B	C	D

Name: _____

Address: _____

City: _____ State: _____ Zip: _____

Telephone: _____

SS # or ONS Member #: _____

RN License #: _____ Other Professional License #: _____

Advocacy in Health Care:
Teaching Patients, Caregivers, and Professionals
Evaluation Form

To assist us in evaluating the effectiveness of the educational design and to make recommendations for future continuing education activities, please complete this evaluation form by circling the appropriate rating.

KEY: 1 = Not at all 2 = Low 3 = Medium 4 = High

1. How relevant were the objectives to the CE activities goal: 1 2 3 4

The goal of this resource is to provide healthcare professionals with an overview of the skills that increase their effectiveness as they empower patients and caregivers to become self-advocates.

To what degree did you achieve the following objectives?

2. Define advocacy and self-advocacy. 1 2 3 4

3. Define commonly used Internet terms. 1 2 3 4

4. Explain criteria used for evaluating the credibility of Web-based information. 1 2 3 4

5. Explain five basic communication skills. 1 2 3 4

6. Present strategies that will help patients and caregivers to communicate effectively with healthcare professionals and providers. 1 2 3 4

7. Compare two decision-making approaches and how they can resolve issues that patients with cancer experience. 1 2 3 4

8. Discuss how patients can prepare to negotiate with healthcare professionals and providers. 1 2 3 4

9. List credible sources that report on healthcare policy and discuss how a nurse can influence healthcare policy. 1 2 3 4

10. How long did it take you to complete the CE activity? _____ minutes

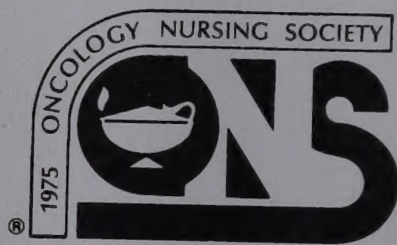11. How will you use this information in your daily practice?_____
_____
_____

Notes

Notes

Notes

Notes

Oncology Nursing Society
125 Enterprise Drive
Pittsburgh, PA 15275
412-859-6100
www.ons.org

INPU0056